# sharing the true stories

Evaluating strategies to improve communication
between health staff and Aboriginal patients



STAGE 2 Report

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**September 2002 to August 2005**

Lakaranhamirr yuwalk dhäwu:
Guŋa'yun YolŋuYolŋuny mala ga djämamirriny mala Yolŋuw märr walal dhu marŋithinyamirr bala-räli'yunmirr.
Dhiyaŋ djämay napurr ga larrum yuwalkku dhäwuw.



A Cooperative Research Centre for Aboriginal and
Tropical Health project

**Project Facilitator:** Kerin Coulehan
**Project Leader:** Isaac Brown

**Project Management Team:** Michael Christie, Gillian Gorham, Anne Lowell, Betty Marrŋanyin and Bhavini Patel

# Acknowledgements

Coulehan, K., Brown, I., Christie, M., Gorham, G., Lowell, A., Marrŋanyin., and Patel, B., 2005, *Sharing the true stories, Evaluating strategies to improve communication between health staff and Aboriginal patients, STAGE 2 Report*, Cooperative Research Centre for Aboriginal Health, Darwin.

# Table of contents

# Participants cited

The many participants, who made significant and sustained contributions to Stage 2 of the *Sharing the true stories* project, are acknowledged in general but remain anonymous within this report. Only members of project management and representatives of the action research teams, who are quoted in the report, are identified below.

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# 1. Introduction

*Sharing the true stories* (STTS), a longitudinal participatory action research (PAR) project (2001–05), has focused on identifying and addressing barriers to effective communication between Aboriginal client groups and health staff in renal and hospital services in the Northern Territory (NT) of Australia. Research has been conducted in two stages, with Stage 1 aimed at problem identification and recommendations for remedial action, and Stage 2 focused on developing and evaluating strategies and resources to bring about constructive change in health service delivery to Aboriginal client and community groups.

The project in total has involved a focus on Yolŋu language speakers from North-East Arnhem Land communities and a subset of Aboriginal patients with end-stage renal disease (ESRD) who access haemodialysis and transplant services in Darwin, capital of the NT. Research has been located largely at Nightcliff Renal Unit (NRU) and Royal Darwin Hospital (RDH) in the metropolitan area, and in a Yolŋu community and associated homeland centre in North-East Arnhem Land.

*Sharing the true stories*, Stage 1 (STTS1) was conducted from January to August 2001. Miscommunication and lack of shared understanding between health staff and Yolŋu renal patients and their supporting family members were found to seriously limit the patients' opportunities and capacities to make informed choices about their health care.

STTS1 findings suggest that:

- **any substantial improvement in communication, and in ensuing health outcomes, requires fundamental change in the delivery of healthcare—in particular, in constructing a shared understanding, from the perspectives of both staff and patients, of physiological processes, renal disease and treatment options (Cass *et al.* 2002:470).**

Research findings from Stage 1 have been disseminated in a number of ways including by means of a report (Lowell *et al.* 2005), an award-winning article in the *Medical Journal of Australia* (Cass *et al.* 2002), feedback for Yolŋu on CD-Rom, and a web site launched in 2004.[1]

STTS1 research identified three key strategies for constructive change to improve communication between health staff and Indigenous client groups, which were to be addressed in *Sharing the true stories*, Stage 2 (STTS2) by:

- ***Shifting Control**—addressing the barriers to improving communication at both system and service levels through increased Indigenous participation in overall management processes and in structuring specific encounters.*

- ***Constructing shared understandings** of key processes and concepts in health care through a sustainable and collaborative process in which staff, clients and others work together.*

- ***Improving communication practices** in intercultural health care encounters through institutional support and strengthening individual expertise. (Smith 2003:5)*

STTS2 was a long-term PAR project conducted from September 2002 until June 2005. The research aim was to improve health outcomes for Aboriginal client groups by addressing the three key areas for change management, namely to improve intercultural communication and develop shared understandings and educational resources, thereby enabling Aboriginal patients and their families to exercise more control in their health care, specifically in interactions with predominantly non-Aboriginal health staff in renal and hospital services.

Yolŋu, and other Aboriginal groups, are often left dissatisfied with the explanations provided by doctors, nurses and other health professionals, and do not believe they are being told the 'full story' or 'true story' (Reid 1983; Weeramanthri 1996; Kemp 2001). The principal Yolŋu researcher insisted on a research model and communication metaphor, which is represented as 'sharing the true stories'.

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[1] www.sharingtruestories.com

# 1. Introduction continued ...

**Ga ŋunhi napurr ŋuli manapanmirr bulu nhakun, dhiyak dhäwuw *Sharing the true stories*—ku yäkuw, ga napurr ŋuli waŋanhamirr, ga milkunhamirr napurr ŋuli nhawi napurruŋguwuy napurr ideas mala, napurr ŋuli gurrupanmirr bala räli, gurrupanmirr bala räli, balanda walal ga napurr yolŋu'yulŋu. Nhathinya walalaŋguŋ guyaŋanhawuy, ga nhathinya napurruŋguŋ guyaŋanhawuy, bala napurr li ŋunhi yoranhamirra ŋurukithi, bala napurr ŋuli manapanmirra. Waŋganydhirra napurruŋguŋ ŋunhi dhäwuny.**

**And when we get together, for this story called *Sharing the true stories*—we talk together, and present mobs of our own ideas, we bounce them backwards and forwards, backwards and forwards, those Balanda and we Yolŋu. What they are thinking, and what we are thinking, then we reach agreement for that (point). Then we are joined together. Our story becomes one.**

# 2. Social and medical context

In northern and central parts of Australia, health staff typically cannot speak or understand the languages spoken by the majority of Aboriginal patients. The patients and their families may speak little English, and often sustain a lifestyle and ways of understanding their bodies, health, disease and treatment that are still strongly determined by traditional philosophies and cultural practice (see, for example, Reid 1983; Devitt and McMasters 1998; Devanesen and Maher 2003).

Even when Aboriginal people speak English or a dialect of English as a first language, serious communication difficulties may occur as a result of the complex sociolinguistic, cultural and political factors which influence communication between different cultural groups (Eades 1991; Harkins 1994: Cooke 1996a, 1996b). When Aboriginal people speak non-standard English, or Aboriginal English, as a first or subsequent language, a 'pseudo intelligibility trap' may apply, with standard English speakers thinking they fully understand speakers of non-standard English or Aboriginal English and vice versa (Harkins 1994:182).

In addition to language barriers, there are differences in culture and world view, which make it difficult to establish common ground between Aboriginal and non-Aboriginal constructions of illness causation and treatment. The Western biomedical model, while appearing monolithic and objective, is in fact historically and culturally contingent, always changing and contested. In the context of communication across cultures, the biomedical approach:

- **is conceptually limited, in terms of the way it looks at and deals with health and illness,**
- **and…it is culturally relative, in that it offers a particular rather than universally**
- **acceptable way of explaining health. (Humphery, Japanangka and Marrawal 1998:20)**

Yet a basic premise of health service delivery is that health staff and patients must be able to communicate effectively in order to achieve sufficient shared understanding for patients to be able to make informed decisions in regard to treatment options and compliance with therapies. Survival of patients with chronic diseases such as ESRD requires an ongoing commitment to therapy by the patient. It is well documented that such a commitment is more likely to be made if communication between patient and health practitioner is effective (Ong *et al.*1995). A shared understanding of issues affecting treatment uptake is essential to optimise management of renal disease, but there is little opportunity for this to occur when communication between staff and patients is ineffective. Devitt and McMasters (1998:165) suggest that the less patients understand what it is they must do and why, 'the more compliance itself becomes simply an issue of 'obedience'.

A discrete group of Indigenous people with renal disease (speakers of the Yolŋu languages of North-East Arnhem Land) was selected for initial focus, as the group comprises a significant proportion of Aboriginal patients who have relocated to Darwin in order to access dialysis services. Yolŋu participants in this project come from one of the larger communities in North-East Arnhem Land or from one of the smaller 'homeland' communities nearby. The larger communities, which were former missions, are now locally self-governing with elected councils and traditional landowners who have the power to control land use under land rights legislation. From the 1960s, Yolŋu have asserted their rights to land by a combination of political and legal action (Williams 1986; Yunupingu, G. 1997) and the movement of many family groups away from the major communities to establish small homeland communities on traditional clan estates (Keen 1994:22).

Within a relatively short period of time, Yolŋu society has undergone profound cultural, social and economic change, although many features of traditional lifestyle have been maintained. Yolŋu typically speak two or more Yolŋu languages from early childhood. English is likely to be their third or subsequent language. Yolŋu languages are still the main languages spoken at home and in most interactions between Yolŋu. Christianity has had a pervasive effect, but traditional belief systems, ceremonial practices and the kinship system remain central to the lives of most Yolŋu (Keen 1994; McIntosh 2000). Yolŋu continue to value hunting and gathering activities, particularly when living in the small homeland centres, but like many Aboriginal groups in the NT, most people have to rely on purchased foods from the community store and take-away food outlets located in the larger communities (Coulehan and Jones 1998:214–222). The majority of Yolŋu either receive social security payments or are on the Community Development and Employment Program, a 'work for the dole' scheme. With little opportunity to move into full paid employment, many Yolŋu are caught in circumstances of 'welfare dependency' that are implicated in the poor health and social malaise evident in many communities (Trudgen 2000).

Renal disease is associated with disadvantage and rapid social transition, together with such factors as changes in diet and exercise and the introduction of alcohol, nicotine and other substances, and the consequences of poor living conditions (Hoy 1998; Hoy *et al.* 2000; Cass *et al.* 2001; You *et al.* 2002; Couzos and Murray 2003:424; Cass *et al.* 2004). The incidence of ESRD among Indigenous Australians is approximately nine times that of the general population, but in some remote communities in the NT it is from twenty to thirty times the national incidence (Cass *et al.* 2001, 2004).

In 2001, Renal Services within the NT Department of Health and Community Services (DHCS) were providing dialysis and transplantation services in the Top End region of the NT for as many as 160 patients, and 90 per cent of patients on haemodialysis were Aboriginal (Gorham 2001:32). Throughout the NT, haemodialysis treatment for the growing number of Aboriginal ESRD patients was available only in the urban centres of Darwin and Alice Springs until the establishment of the Tiwi Dialysis Centre on Bathurst Island in 1999 and the Katherine Dialysis Unit in 2000. Yolŋu and other Aboriginal people from remote communities who require hospital and specialist health services have, by necessity, to relocate to town, where they and their accompanying families experience such social costs as alienation and housing problems (Coulehan 1995).

In the latter half of 2003, NT Renal Services commenced the groundwork to establish self-care home haemodialysis (HHD) services in remote communities. This included the design and development of small relocatable dialysis units and extensive community consultation to determine dialysis sites and negotiate agreements to assist and support patients managing their treatment in home communities. In June 2004, the HHD program was officially launched following the opening of a dedicated training facility at NRU in Darwin and the appointment of a senior renal nurse with a background in cultural awareness programs and train-the-trainer qualifications.

At that time, the renal unit in the suburb of Nightcliff was at capacity, with eighty haemodialysis patients attending, while a further eight patients dialysed at the Tiwi Dialysis Centre on Bathurst Island. The renal ward at RDH managed the overflow of patients and acute dialysis with a capacity, in double shifts, to dialyse ten to twenty patients per week. In September to October 2004, seven haemodialysis patients were relocated to the newly established renal unit at Palmerston, a satellite town adjacent to Darwin. By March 2005, there were sixteen patients accessing the facility at Palmerston.

By June 2005, NRU had trained nine Aboriginal patients in self-care HHD, each with an identified supporting family member or 'buddy'; three patients and their 'buddies' returned home to their communities of choice, including one Yolŋu patient who chose to continue self-care HHD in a private non-Aboriginal family household in Darwin. A further two patients were ready for placement and were waiting for the dialysis facilities to be completed in their home communities. Of the remaining four patients, one initially withdrew from training following lack of attendance but subsequently indicated a willingness to restart training, another withdrew voluntarily, while the third Aboriginal patient chose to self-care dialyse at NRU. Unfortunately, one patient died unexpectedly just prior to relocation home, but the supporting family member, who was already fully trained, has expressed a willingness to be a 'buddy' for another elderly patient in HHD to facilitate her return to their community.

Following the influence of the STTS research project, interpreters and an interpreter-mentor have been utilised in the HHD program to explain the training process and patient and staff responsibilities, and in community consultations and negotiations in regard to patient support and establishment in home communities. Due to the interest in returning home and the backlog of patients waiting to be trained, NRU management was planning to commence a second shift of training in self-care HHD, increasing training capacity to four patients at a time.

From the outset of STTS2, Yolŋu research participants have constantly been asking when dialysis services will be made available in their communities so that patients and supporting family members might return home. The long-term project was designed to include Yolŋu participation in Darwin and in a number of remote communities in the collaborative development and evaluation of communication strategies and educational resources. While the specific focus was on Yolŋu patients and supporting family members who access renal and hospital services in Darwin, research strategies and resources have wider application in health services to Aboriginal client and community groups.

# 3. Theory and methods

The research paradigm was chosen to accommodate both Yolŋu and Balanda ways of communicating and negotiating meaning.[2]

From a Western point of view, the research theory and methodology has been based on PAR (Green *et al.* 1994; Piggot-Irvine 2003, 2004), qualitative methods and constructivism (Guba and Lincoln 2005). The research approach was inductive, utilising techniques from grounded theory in data analysis and interpretation—that is, building theory from the data (Strauss and Corbin 1990; Christie 1994; Higginbotham, Albrecht and Connor 2001).

In using a constructivist paradigm, the aim of inquiry was, first, to develop among research participants an awareness of the competing 'constructions' of knowledge traditions and communicative and educative practices that initially shaped staff/patient/family interactions in hospital and renal care and, second, research strategies were designed to 'reconstruct' or develop personal skills and bring about change, within institutions and system-wide, in order to achieve effective communication and shared understandings in Aboriginal health.

PAR methods were identified as being a collaborative and inclusive framework for change management within institutions and across systems.

Following PAR methods, the project sought to:

- develop respectful, trust-based and open relationships
- use individual change to leverage institutional change
- incorporate different cultural perspectives and knowledges
- overcome the gap between research aims and research action
- use the 'double loop learning' method (Piggot-Irvine 2003:5) of reflection and evaluation to lead to change management and best practice.

Historically, collaborative action research has proven hospitable to a Yolŋu theory and practice of knowledge transmission and intercultural communication as applied in 'both ways' education contexts (Yunupingu, B. 1991:103; Henry and McTaggart 1991:7-9). As Mandawuy Yunupingu (1994:10), a Yolŋu leader and educator argues:

> **Balance between different points of view is possible. That's what our Yolŋu life is all about. Balancing difference between Yirritja and Dhuwa (moieties), between women and men and so on. Aboriginal and non-Aboriginal Australians can value and protect their differences while still finding ways to work at balance.**

The STTS2 project was designed to incorporate, as thoroughly and as equitably as possible, the contribution of a specifically Yolŋu ontology and epistemology. Yolŋu ESRD patients, members of their families and Yolŋu registered interpreters have participated as co-researchers and their perspectives and methodologies have been incorporated into the research process. The research team also included predominantly non-Aboriginal health staff, health researchers, linguists and multimedia consultants, many of whom have had extensive experience working with Yolŋu.

The value of collaboration with Yolŋu participants is reflected in the project title and focus and in the planning and conduct of the long-term research project.

[2] Yolŋu Matha speakers of North-East Arnhem Land use the term Yolŋu to designate themselves, and by extension other Aboriginal people, and the term Balanda to refer to non-indigenous people of European descent.

# 4. History and structure

The period of project agreement for STTS2 was initially from September 2002 to March 2004, but the project was extended until June 2005. The collaborative development and evaluation of intercultural communication strategies and health education resources proved to be a complex and lengthy process.

The participation of Aboriginal client and community groups and health service providers was canvassed at a number of meetings and workshops including:

● a workshop on PAR methods, held in February 2003 at the Northern Territory University (subsequently renamed CDU), which aimed to increase understanding and to build the capacity of project participants in PAR theory and methods; and

● a STTS2 project meeting, held at the Mirambeena Resort in Darwin on 28 February 2003, to communicate information about Stage 1 findings and Stage 2 strategies, and to invite Yolŋu participation in the second stage of research.

## Reference group and research ethics

The Yolŋu and other Aboriginal participants who met at Mirambeena were meant to play a continuing role in the research project as an Indigenous Reference Group, but this did not eventuate; however, a subset of Yolŋu renal patients, supporting family and community members, and Yolŋu interpreters became participant researchers. Wider consultations were held with Yolŋu in Darwin and a number of Yolŋu communities in North-East Arnhem Land.

Project participants consulted with Yolŋu in Darwin and in the remote communities for purposes of research ethics and informed consent, and application for ethical clearance was obtained from CDU Human Ethics Committee. To facilitate the informed consent of Yolŋu participants, explanatory audiotapes in Yolŋu language and consent forms written in Yolŋu were used. All other participants signed consent forms written in English. As the project was long-term, and participants entered and exited the project, the informed consent process was ongoing.

## Project management

The project management team represented the key stakeholders and its composition was remarkably stable over time. Continuity of membership was provided by the project leader, the principal Yolŋu researcher, a CDU linguist experienced in Yolŋu language and culture, a consultant in intercultural communication, and one or two health professionals, who held managerial and professional positions in renal and hospital services at NRU and RDH.

The project leader was an Indigenous academic located at the School of Australian Indigenous Knowledge Systems at CDU. His experience in Indigenous research ethics and collaborative relationships with the CRCAH and Aboriginal Medical Services Alliance Northern Territory shaped the authority of project management and the project's links to Aboriginal health research, education and training organisations.

The principal Yolŋu researcher was a senior Yolŋu woman with in-depth knowledge of Yolŋu languages and culture and experience in linguistics in teaching/learning contexts. As a renal patient, registered interpreter and community elder, she was well positioned to represent Yolŋu interests in her dual role as a member of project management and consultant researcher working with the three action teams.

An interim evaluation report on the early phase of STTS2 (January to June 2003) identified a number of concerns, including an apparent lack of clarification of the PAR approach and process, and of the roles and responsibilities of project members. There was also concern within the STTS2 teams that the concept of external evaluation did not fit easily with the PAR approach.

Initially, project coordination and evaluation involved two positions—a project coordinator, to support project management in matters of administration and research responsibilities, and a project evaluator, to provide an independent evaluation of the research process. When the two positions became vacant in June 2003, project management decided that an external evaluator was not required and appointed a project facilitator instead, as consistent with the original project plan.

The project facilitator provided supervision and mentoring to junior researchers and administrative support to project management in relation to CDU and CRCAH reports and submissions, and facilitated publicity. Administrative support was given to the action teams and to documentation procedures. In October 2004, the project facilitator prepared an interim report, and in April 2005 was re-engaged to assist project management with the wind-up of research activities, including the final report and budget acquittal to the CRCAH.

Project management met on a three-monthly basis, or more frequently, initially alternating between venues (but, since August 2003, at NRU to maximise the opportunity for renal staff to participate). Project management oversaw three action teams, A, B and C, and combined meetings of All Teams, when the three action teams coalesced to report on their respective team's PAR.

All Teams, that is project management and action teams A, B and C, had a schedule of monthly meetings established in September 2003 and maintained until November 2004. This important initiative, which allowed research participants to meet and share their PAR, became the framework for all the action teams to meet with project management to share and document their PAR and decide upon follow-up action. In this context, wider discussion, reflection on research process and evaluation of developing strategies and resources was facilitated and documented.

## Action team management

The action teams—Action Teams A, B and C—were the groups that carried out the project. These teams comprised health staff, research consultants and a number of Yolŋu patients, family members and community elders and Yolŋu registered interpreters and translators who were engaged as research consultants. Yolŋu participants were contracted either on AIS contracts, for interpreters and translators, or on CDU casual researcher contracts for patients and family and community members who were not registered with AIS.

In addition, the three action teams had the support of three consultants in intercultural communication who worked with particular teams on their individual strategies and also, at times, across the three teams. An interpreter-mentor, an Aboriginal Resource and Development Services (ARDS) consultant on contract to DHCS in association with AIS to mentor and train interpreters 'on-the-job' in health interpreting, was a significant resource. The interpreter-mentor, a registered nurse with post-graduate nursing qualifications and knowledge in Yolŋu language and culture, worked with Yolŋu interpreters and health staff across the three teams, both in strategies to bring about effective use of interpreters in hospital and renal services and in the development of STTS educational resources. A consultant in intercultural communication and a CDU linguist also supported individual action teams and worked across the three teams to support the development of intercultural communication strategies and education resources.

Multiple perspectives and different knowledge backgrounds were brought to the project by Yolŋu participants in Darwin and remote communities and health staff based at the suburban renal unit and the public hospital in Darwin. Participating health staff included clinical nurse managers, nephrologists and other specialist doctors, nurse educators, renal nurses, and a pharmacist, a dietician, a social worker and Aboriginal liaison officers. CDU-based researchers and other consultants provided expertise in linguistics, intercultural communication and the production of multimedia for educational purposes.

Members of Action Teams A, B and C met regularly within their own teams to plan, action and reflect on their respective research activities. The location of these meetings varied and included Yolŋu priorities for time and venue. Some action team meetings were held in remote communities in Arnhem Land for consultation purposes and for the evaluation and cultural validation of the collaboratively developed intercultural communication protocols and health education resources.

# 5. Research teams and strategies

The three action teams reshaped their memberships over the timeframe of the project as participants entered and exited the project. Typically, the three teams had core participants who maintained continuity within their respective teams and some individual researchers including health staff, consultants and Yolŋu researchers worked across the three teams.

Initially, each of the teams took responsibility for addressing one of the three key areas for change management. Over time it became apparent that there was considerable overlap in the aims and activities of the teams as collaborative research and change management required action across the three strategies. Project management and the facilitator helped to develop and support the links between the action research and evaluation of the three teams.

## Shifting control

Team A took responsibility for action research and change management at institutional level. At NRU, encounters between health staff and patients and their families were restructured to better accommodate the needs and preferences of the patients.

The CDU linguist identified the need to:

- **change the way in which the arrangements at the renal unit particularly worked, so that people with the same language would have a chance to be together as often as possible, and talking about their own agendas, and that they would somehow be in a position for the white health professionals to be responding to them.**

Some health staff argued that the project favoured a clinical focus and marginalised the social concerns of patients and families in renal care. As staff found that there were difficulties in working across the boundaries of clinical and social services at NRU, the strategy to group Aboriginal patients by language groups with an interpreter present to facilitate communication was tested in both a clinical and a social review process.

Staff arranged with Yolŋu patients, as a trial group of Aboriginal patients at NRU, to attend haemodialysis clinics as a distinct language group, with an interpreter present to facilitate communication with renal staff. This initiative demonstrated that Yolŋu patients benefited from the opportunity to voice their concerns in language and as a group. Staff benefited because hitherto 'silent' patients spoke up about such matters as pain and nurses' techniques in needling into the fistula.

As a participating Yolŋu patient explained, the haemodialysis clinic by language group with interpreter present overcame the reluctance of individual patients to question procedures, because they were able to talk among themselves and found they had similar concerns. The principal Yolŋu researcher noted that:

- **during doctors visits, we (people) from Galiwin'ku, and Yirrkala, oh no, Milingimbi, Lake Evella and Ramingining, we become one, like come together. She is there with us the doctor, and nurse, and interpreter all there. And we all talk, discover, that is good. We as one group go together and we talk with the doctor…We are not embarrassed, so that we help each other.**

A social review process was also trialled with a small group of Yolŋu patients who, with an interpreter present, met with the clinical nurse manager, social worker and Aboriginal liaison officer to discuss patients' concerns of a non-medical nature. Patients' telephone access to, and while at, the renal unit was the first topic for the social review process. Phone access, housing, other relocation problems, which impact on patients' health and therapy compliance, are typically addressed by a social worker and Aboriginal liaison officers at the renal unit. Participating researchers, staff and patients, decided that there was scope for these matters to be discussed in a social review process, with interpreters participating, and with Aboriginal patients more involved in the problem identification and resolution process.

As a result of this meeting, all patients, not just the Yolŋu participants, benefited from the installation of a toll-free number for in-calls to the renal unit and distribution of an information card with key telephone contact details for medical, housing and income support. This small yet significant initiative provides Aboriginal patients with more control in their circumstances of renal care, and has the potential to improve health outcomes by means of more effective staff–patient communication about social and medical concerns.

It proved difficult to arrange the clinical and social reviews by language group and with an interpreter present on a regular basis. Inhibiting factors included limited access to experienced interpreters across the range of language groups in the patient cohort and turnover in management and staff at the renal unit.

The clinical nurse manager (CNM) at the time could see the importance of group identity among Aboriginal patients and of institutionalising the use of interpreters.

> **If it was a regular occurrence then people would (be) more likely to speak to them and it would travel down the line to us. It's just been unfortunate that hasn't worked the way we hoped it would. We got some good things out of it though. We were able to go through and ask everyone what name they would like to be used, or called by, and that was changed on the medical records. And we redefined, I suppose, some of the so-called community language groups that we probably didn't have accurately collected …I still would like to see that regular interpreter on site as a way of tracking what people really feel.**

This aim to institutionalise use of interpreters at NRU was held onto, and early in 2005 renal unit management set up a twice-weekly booking for interpreters from different language groups to alternate in the dialysis area.

Another initiative to restructure patient/staff interactions, and to give patients and their supporting kin more control in their renal care, arose after a training facility for self-care HHD was officially opened at NRU in May 2004. Since then, renal staff have been training Aboriginal ESRD patients and supporting kin or 'buddies' in self-care HHD in preparation for repatriation to remote communities.

The NT Renal Services Development Officer, who was charged with oversighting the introduction of satellite renal services and the option of HHD for Aboriginal patients trained in self-care, joined project management at this time. It was by her authority that the research process was extended within the renal rollout to community consultations about HHD and the training of Yolŋu patients and 'buddies' in self-care dialysis.

In addition, a former CNM at NRU took up new responsibilities in training renal patients and their buddies in self-care HHD and managing the repatriation process. In this new role, she continued to participate in the PAR project, working with other health staff, an interpreter-mentor, and Yolŋu interpreters, in the design of an educational resource explaining the dialysis machine and dialysis process.

Team A was not linked to the resource development dimensions of STTS2 until late in the project when members of Team A collaborated with Team B, including participating Yolŋu, in the development of the dialysis 'machine story'. This context provided opportunity for significant collaboration towards improving communication, sharing knowledge and shifting power in renal services. Initiatives led by project participants included community consultations, training of patients and education of their supporting kin in preparation for self-care HHD.

## Constructing shared understandings

Within the project budget, Team B had a separate allocation in the form of a substantial grant from AMGEN Australia, a pharmaceutical company, for the development of educational resources in the renal care context. Before it could begin to develop resources, Team B had to work at developing mutual respect and culturally appropriate methods to share knowledge between participating health staff, Yolŋu patients, family and community members and Yolŋu interpreters.

Activities such as 'bush tucker' trips in the environs of Darwin were arranged regularly, not merely to provide patients with exercise and traditional foods in a cultural setting, but as a strategy to build trust and shift the balance of power in relations between patients and health staff. In this context, Aboriginal patients and family members became the experts and the staff the learners.

Only after this initial process of building relationships and sharing knowledge, was it possible for Team B to engage with educational media consultants to design and develop resources on the respiratory and circulatory systems, kidney function and haemodialysis, which Yolŋu termed the heart, lung, kidney and dialysis machine 'stories'.

Yolŋu have insisted on exploring knowledge about the body, physiological systems and dialysis in Yolŋu language and metaphors. Yolŋu participants worked with Team B on developing a metaphor and an educational resource on dialysis. The principal Yolŋu researcher commented on the cultural significance of this resource.

- **The cycad nut (story) is just like the kidney machine (story) that washes away the**
- **poison from our body when we are on dialysis. The cycad story is so special in Yolŋu**
- **culture…and we have brought this matter to share with our Balanda friends.**

Researchers soon realised that it was more appropriate to start with the 'full story' by sharing knowledge about the body and physiological systems, rather than starting with pathology. The interpreter-mentor noted that:

- **health professionals always start from the point of pathology and the (Yolŋu) said they**
- **would like us to start at the start of the story, which is what is the function of the organs**
- **in the first place. Instead of talking about kidney pathology, talk about what kidneys do**
- **in the first place, so that the pathology becomes meaningful.**

An original aim was to collaboratively develop multimedia resources about the human body that transcend language and cultural representations and that are meaningful to health professionals and Aboriginal client groups. The CDU linguist highlighted the difficulties in achieving this goal.

- **There's something about the human body which is as material for anybody as it is for**
- **anybody else. And we could have spent more time trying to find ways of generating**
- **agreement on the nature of that thing, and my idea was to do that through**
- **collaboratively producing multimedia little graphics, or little flash animations that you**
- **could see and talk about, that didn't assume that there was a Balanda story and a Yolŋu**
- **story that pre-existed the possibility of those representations. Because that was so**
- **difficult, we did sort of fall back on let's tell the Yolŋu story about this one, let's tell the**
- **Balanda story about this one. And then it was very difficult to actually either find a way**
- **of representing it that meant something to everybody equally, and also maybe that**
- **was going to be useful outside to other language groups as well. And I think we can get**
- **there…**

Before intercultural educational resources could be developed, health professionals and consultant researchers had to decide on base concepts in biomedicine and develop, in consultation with Yolŋu interpreters and the interpreter-mentor, plain English 'stories'. The interpreter-mentor noted that:

> **Yes, we had to agree and sometimes that took a lot of teasing out. You know, what do we really mean by 'metabolism'. And the pharmacist will be coming from one slightly different perspective, a nurse will come from another, a dietician from another, so teasing out what is the base concept and putting that into plain English.**

> **First of all we needed to gather the up to-date, correct data, make sure we all understood what (we) were talking about. And then put it into plain English, sometimes reducing…complex concepts to plain English and then agreeing on what that plain English should be. Then going to dialogue with the people, all the time using good visuals.**

Initially, the focus on Western biomedical knowledge led to meetings being held indoors at NRU, less frequently at the hospital, and typically involved sitting around a table or on the floor with access to lap-top computers and text-books. It soon became apparent that if Yolŋu were to participate fully, their comforts and preferences needed to be taken into account. As the principal Yolŋu researcher put it:

> **We don't just sit and work in that one place, in the renal unit, not (always) in that room. We also want to sit and work outside, on the grass, or over there at East Point, or Fannie Bay, or Buffalo Creek, like that we go out (to these places). No just sit inside one building. So that we can look out at country…We have finished the (stories) about breath and heart, two stories, okay…But those stories are only in English, and we also want to put Yolŋu language into those stories.**

An important part of Team B's action research has been to reflect on, modify and document changes in its communication and education practices in order to better accommodate Yolŋu ideas and methods. Within the PAR process, participants developed techniques to work together to improve communication, achieve shared understandings, and enable patients and their supporting families and communities to be better informed and participate more fully in their health care. The mechanism of working together, achieving shared understandings and developing educational resources was coined 'story methodology' by research participants.

In reflecting on the research process, the interpreter-mentor noted that:

> **the methodology that we discovered along the way could be applied to learning about anything…If you used language, took world view into account, had time to do dialogue, had good relationships, that everything we discovered in this 'story methodology' that (the participant) could learn anything.**

Doing dialogue required interpretation and translation between English and Yolŋu Matha speakers. Health staff and Yolŋu participants needed the intermediary skills of Yolŋu interpreters and translators, and an interpreter-mentor and a number of consultant researchers who had knowledge and skills in Yolŋu language and culture and in intercultural communication. The CDU linguist highlighted that:

> **One of the interesting things…that came out of the project is a new understanding of the way translations get done. The very first *Sharing the true stories* meeting we had, (the principal Yolŋu researcher) came along with a thing that had been written in English about how the kidney works and then it had been laboriously translated into a Yolŋu language, and had lost some of its meaning…It became clear that just talking through that notion of sharing stories and the way in which shared understandings are built up, we found that it was a much better idea to have people in the group talking about the ideas that were around something, and then to record those conversations and edit them in…a collaborative effort for building knowledge. And the way people bounced their ideas off each other, or helped each other to clarify things, actually became quite key to that process of building shared understandings. And I think every now and then we retreated from that because it's not that easy to organise. But I think that one of the things that have come out of the research is a very good re-definition of the process of translation and the sorts of things that need to be done in order to make it happen properly.**

## 5. Research teams and strategies continued ...

Group discussions about the heart, lung and kidney and dialysis machine 'stories' involved video recording of discussions in English and Yolŋu Matha and interpreting and translating between the two languages and world views. In addition, the audio and video tapes of interactions and activities were transcribed into Yolŋu and English text, both for the purposes of developing educational resources that had wider potential in Aboriginal health and to record and document participants' PAR reflections.

Research participants took all resources in development stage to a major Yolŋu community and a number of smaller outstations. Participants were invited to consult with a number of community groups at times and locations of their choosing, which included consultations in council office space and at night around a campfire. Multimedia resources as well as role-play were used to demonstrate the health education stories.

On one visit to a Yolŋu community, Team B found role-play to be a useful educational method not dissimilar to Aboriginal methods of knowledge transmission in ceremonies. As the interpreter-mentor states:

> **We discovered just by chance one day…that role-playing was a very effective way to teach anatomy and physiology. And when you think about it, that should not really surprise us because Aboriginal people do carry a lot of their information in dance, which you could say have actions and do tell a story. We were able to do a role-play that demonstrated circulation of blood around the body and some of the functions of the kidney. What we discovered was that this was one of the most effective ways to share this Western biomedical information, and when we used that medium that's where we got the most responses, the most questions from people, the most engage(ment).**

While Yolŋu participants did engage with learning from books and web sites about Western biomedical knowledge, they also asserted their preference to learn in action. One Yolŋu researcher made the point that, rather than learning from a manual or text, she preferred 'looking at the (dialysis) machine and discovering it myself'.

An opportunity presented itself for Yolŋu learning in action when training in self-care HHD commenced at NRU. Team B, including Yolŋu interpreters, worked with a Yolŋu patient to develop an educational resource on the dialysis machine and process. The DVD was made in Yolŋu Matha for a target audience of Yolŋu renal patients, families and communities and Yolŋu interpreters working in renal services. The principal Yolŋu researcher described a community consultation process focused both on informing the community about HHD and evaluating a developing resource on the dialysis 'machine story'.

> **At that time we were at (a homeland centre) and met them, and we ate food they gave us. After that we showed a picture to them, showed a video to them, (the multimedia man) had taken a video, um, carried a video and also brought a television in his car…And in that *bittja* we showed them a story about dialysis, that (a Yolŋu patient) is telling. This (patient) is one (Yolŋu) patient who is ready to return and go back to (her home community). Because she knows, by herself she can work those buttons, join up the tubes, turn on the water and other things. Calculating for herself, and work everything, go up on the scales. And also she insert (the needles) into her arm by herself. Do the work all by herself, and now she is ready to live at (home).**

In this way, community elders learned how Yolŋu patients were training in Darwin in self-care haemodialysis in preparation for returning home. They were able to comment on and validate the educational resources as collaboratively designed and produced. Community consultations were only one method used to address the project's aim to improve communication practices within the scope of the project and more generally in health service delivery to Aboriginal client and community groups.

# Improving communication practices

In addition to project funding, Team C had short-term, specific-purpose funding in the form of a Safety Innovations in Practice Program grant for research focusing on reducing the risk of miscommunication in Indigenous health care. This funding enabled Team C to engage consultants in intercultural communication and information technologies to contribute to the team's aim to develop and implement strategies to educate health staff about Stage 1 findings, and develop guidelines for effective use of Aboriginal interpreters and the project web site.[3]

The Director of Anaesthesia at RDH participated in Team C and recognised the potential, and current limitations, of the web site as a resource for health staff.

> **The web site, it is good. In a way, I think it was a bit before its time. I guess we've had all the issues of who maintains the server, and all those technical side of things that haven't been completely addressed yet. Even the fact that many of (the) staff in the hospital don't have access to the internet, we've tried to get it on the intranet (but) because of lack of resources in the Health Department getting those things working together hasn't yet happened. So I think although the web site has been around for a year or more, it still hasn't got the utilisation it could have because those issues have, in a way, held it back.**

Resolution of issues to do with the long-term maintenance of the web site and links between the staff intranet and the internet has proven elusive within the project timeframe. A more achievable and partial solution has been identified by research participants at RDH, where the STTS web site has been book-marked on all computers with internet access, so that hospital professionals have ready access to this resource and its guidelines on effective communication in Aboriginal health.

The web site and STTS1 findings, copied on CD-Rom for Yolŋu, and Aboriginal Interpreter Services Guidelines were launched by the Minister for Health when he officially opened the self-care training facility at NRU on 31 May 2004 (CDU 2004a).

Yolŋu participants and health staff demonstrated STTS resources. The principal Yolŋu researcher reflected on this public event:

> **That's very good when we presented our work, how we work in the Renal Unit, and what we produce during the opening launch day of the Renal Unit on the 31st of May last year. We placed displays inside, and also at the same time when the Minister for Health went there. He opened that renal unit building, on the other side that small renal unit (self-care training facility) that is going over to Galiwin'ku. The same type that is going over to Groote or Maningrida, okay.**

The simultaneous launch of the project web site and Aboriginal Interpreter Services Guidelines with the official opening of the self-care dialysis training facility at NRU, during National Kidney Week 2004, served to engage policy-makers and raise public awareness of the need for more effective communication about kidney disease and treatment options. The project leader suggested that:

> **One of the other really interesting things, I think, that happened following that official opening of the project research was the interest that the Health Department showed in the project. We had enough people from the Health Department being involved in a lot of our sub-groups that were doing part and parcel of the research, wherever they could…It certainly, I think, gave us an impetus…and I think this is how policy is developed.**

A subset of Team C focused on improving communication at RDH. The Director of Anaesthesia at RDH led the team, and coordination roles were alternated between a number of health professionals. This group comprised health professionals, a consultant in intercultural communication and a multimedia consultant, together with an interpreter-mentor and Yolŋu interpreters.

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[1] www.sharingtruestories.com

Participating RDH health staff developed a number of initiatives to promote the profile of Aboriginal interpreters and to educate staff in effective use of interpreters in the hospital context. For example, they developed a staff information card about AIS and this card was clipped to health staff identity badges and worn while on duty at the hospital. The Director of Anaesthesia and the Cultural Consultant at RDH were two of the project participants who supported this initiative.

- **a little thing like a card that we made…for interpreting services…We sat down and spent a few hours working out what to put on it, and then it takes a bit of an effort, but it just becomes a resource that is available…It was part of the project, it wasn't a core thing, but it's something that wouldn't have happened if we hadn't put all those people from *Sharing the true stories* together…(Director of Anaesthesia)**

- **It's just another one of those things that creates awareness. (Cultural Consultant)**

In the main, research activities at RDH were managed by in-kind contributions of participating hospital staff. Later in the project timeframe, RDH participants secured a small grant from their health professionals' association, which enabled them to pay consultants in intercultural communication and multimedia to work with Aboriginal interpreters to design, film and act in a video to educate health professionals in the need for effective use of interpreters in the hospital setting.

On 18 August 2004, the video titled *Getting serious about communication in Aboriginal health* was officially launched by the Minister for Health, accompanied by the Minister for Community Development, in the foyer at RDH. At the launch, Yolŋu marked the importance to them of effective communication in hospital and renal services, with a ceremony performed in the hospital foyer to present non-Aboriginal policy and decision-makers with traditional message sticks (CDU 2004b).

The principal Yolŋu researcher described the significance of the Yolŋu message stick ceremony from her cultural perspective.

- **(The Yolŋu elder) sang songs, and the young men and women dancers (performed) in a procession. At that same time they carried that letter stick, two letter sticks. One letter stick they brought and gave to the Minister for Health, and one letter stick they presented to (NT Renal Services Development Officer). So that those stories would be on those two letter sticks. That 'letter stick' (name) is Balanda language, and our Yolŋu name is *dharpa dhäwumirr*…And that ceremony you saw at the hospital, they were paddling, they were paddling, carrying that message from another place. So that other Yolŋu will hear that message, and that's what (is) happening now. That story is like, like when Yolŋu go to another country and take a good story about medicines, and what ever other things that those people don't know about. Those letter sticks were like that, like a person with a message flies from here to another country, okay.**

The Director of Anaesthesia at RDH, who played a leading role in Team C's development of the "Getting serious' initiative, commented:

- **there had been a large number of people involved in the production of the video and a lot of people have worked very hard for the interpreter service, and to raise the profile and to at least get a little bit of political acknowledgment…Because there aren't many things that two ministers will come to in the hospital, and they were prepared to come and senior management in the hospital came along, so at least they are aware of the project and the issues.**

The STTS2 project has, as a whole, engaged policy-makers and middle management in DHCS (NRU and RDH) and the Department of Community Development, Sport and Cultural Affairs (AIS) by means of public events and associated publicity.

Perhaps less obvious, but equally significant, has been the actions of individual participants in the project whose roles and responsibilities within institutions have given them opportunities to bring about change management and best practice in service delivery at NRU and RDH, and to begin to extend research strategies, protocols and resources across hospital and renal services in the NT. The responsibilities and multidisciplinary expertise that health staff brought to all PAR teams constituted both the strength of and a challenge to collaborative research.

# 6. Challenges and limitations

Workshops held at the start of STTS2 had provided some participants, including members of project management, with a limited understanding of PAR methods as related to change management within institutions and across bureaucratic systems. While members of the project management team, including the facilitator, supported the action research teams, participants' limited understanding of PAR theory and method, and consequently of commitment to the reflection, feedback, and documentation process, remained problematic.

## Reflection and documentation

The Director of Pharmacy at RDH, who was a member of project management and a member of Team B, recognised that health professionals found working in PAR to be unfamiliar and challenging.

> **I think some of the problems that we have had in terms of engaging and participation of people at the renal unit or people at the hospital is that because they're not comfortable with collaborative processes, because we work in a very hierarchical system, and we work with very quantitative outcomes…asking people to do self-reflection is actually quite challenging for them. And so to be able to present a documented methodology like PAR as an introduction to the process that the project was trying to get people to engage in, I think, was very useful.**

The original plan to hold workshops regularly to promote collaboration and PAR methods was only acted upon once (Smith 2003:9). The introduction of a monthly schedule of All Teams' meetings in the auditorium at RDH, that included the participation of project management, only partially compensated for specific training in PAR theory and methods. During the long-term project, participants came and went so that at any given time there were participants who had not been formally introduced to PAR theory and methods, even though they had formally consented to participate in the action research process. Not surprisingly, a minority of participants distanced themselves from full participation in the PAR process and some were reluctant to commit their PAR reflections to paper or electronic copy for collation and documentation purposes.

Initially the project had a coordinator and an evaluator who respectively took responsibility for administrative matters and evaluation of PAR. After these two positions were collapsed, the project facilitator was responsible for the documentation of administrative procedures such as minutes and action notes and the collation of the PAR activities and reflections of all teams. This mechanism was arguably not the most appropriate method for groups to have their PAR documented, but it was a default position when action team members, including busy health professionals, found it difficult to maintain a group reflection and documentation process. The consultant in intercultural communication argued that:

> **if you look at the way action research is supposed to happen, you have a group and you reflect within a group so that it's discussed openly, there's a good level of trust and clear communication because you're all listening to each other, you can clarify, you can ask questions, you can argue or do whatever. This is the way action research happens. It should be very much a dynamic process within the group and a collaborative thing. What happened with this project is that at different times, instead of reflections happening within the group, people were invited to reflect outside the group. So information would be sent by email or done in interviews and then re-interpreted and sometimes fed back with a lot of misunderstanding happening.**

Yolŋu participants were largely excluded from this reflection and documentation process due to issues to do with literacy and email access. As partial mitigation against these problems, each team conducted informal oral briefings and occasional video presentations at the combined All Teams' meetings at RDH, which allowed for the sharing and documenting of activities and reflections in ways that were more inclusive.

## 6. challenges and limitations continued...

Project management recognised that project responsibilities required certain administrative procedures with which Yolŋu participants were not familiar. Also it was apparent that Yolŋu PAR was more effectively conducted in the smaller action teams rather than in the larger meetings of All Teams. The CDU linguist summarised:

- **I think…for the whole overall project there is a whole lot of administrative stuff that needs to be done that if you try to involve some Yolŋu in that process using formal Balanda processes of meetings and minutes etcetera, it becomes very difficult. So I think that the administrative side of it needs to be looked after by administrators and the research stuff needs to be done in small collaborative groups, and it's important to have those groups talking to each other regularly, which I think we achieved pretty satisfactorily.**

While there was a continuing need for project management and action teams to meet, share information about separate strategies and initiatives, reflect on and evaluate work in progress and document this PAR process, there was evidently a need for another way to foster the sharing and documenting of ideas and activities within smaller groups that was more inclusive of Yolŋu contributions.

As video recording was being used extensively in the development of communication and education strategies and resources, video recording was also used to capture and preserve project participants' comments on research activities and critical reflections on research process, including that of Yolŋu participants speaking in Yolŋu Matha.

## using multimedia

In the main, multimedia used for communication and education purposes proved to be compatible with cross-cultural PAR and with a Yolŋu preference for communication and education in story-telling and performance modes. There were limitations, however, particularly in the extent to which Balanda dominated the technology side of using multimedia for communication and education purposes, and also in terms of reflecting on and documenting the relationships and logistics involved in working with and in multimedia formats in health contexts. The Director of Anaesthesia at RDH noted:

- **I don't know how well PAR worked for the web site. I think because of time constraints and technical issues, there was a small number of people who did a lot of work and have made it happen. And they actually tried to get participatory action in it, but in that part of the project it probably was the least successful in terms of participatory action, although we ended up with a good resource there.**

Other participants saw Yolŋu contributions as being more in the language and culture domain and were not particularly disturbed that Yolŋu were typically not operating the video camera or using the technologies in their participation in the project. Yet there were participants who saw the need to transfer knowledge and skills in the use of both health and education technologies. Team A and Team B's work with Yolŋu patients and their 'buddies' and Yolŋu interpreters in the training in the self-care HHD context was a major example of PAR leading to the sharing of knowledge and skills in regard to the technicalities of the dialysis machine and dialysis process. Smaller but significant efforts to share with Yolŋu researchers the knowledge and skills of a technical nature, for example in the use of lap-top computers and how to search a web site or prepare and operate a PowerPoint presentation, were made by action teams in the course of developing resources and making presentations at workshops and conferences.

Project teams developed and are continuing to evaluate a whole new education support program in print, video, CD-Rom, DVD and web site formats. Technical problems have surfaced that have challenged project management and action teams to find ways and means to work around or overcome these potential limitations to research dissemination and transfer. As already noted, the STTS web site is not immediately accessible to all health staff, who typically have health intranet access only in the workplace. Static CD-Rom versions of the web site need to be constantly updated as new resources and related links are uploaded to the live web site.

The first batch of STTS2 resources developed and distributed for evaluation and cultural validation purposes was in CD-Rom or video format. These resources were widely circulated in NT health education contexts, together with a mailed questionnaire, which was designed to elicit feedback on use of educational resources in Aboriginal health care in general, and of the accompanying STTS resources in particular. The questionnaire proved to be an ineffective mechanism for obtaining feedback on the resources, as too few recipients responded. Consultations with Yolŋu client and community groups and with health staff at in-service workshops and cultural awareness programs in Darwin, in a number of Yolŋu remote communities, and in hospital and renal service contexts elsewhere in the NT have provided opportunities for evaluating developing resources.

During the timeframe of the project, DVD has rapidly been taking over from video in the home entertainment sector, including in the homes of health staff and of Aboriginal clients both in town and in remote locations. A second production run of STTS resources has been made in DVD format and these resources are due to be released at the end of the project.

Components of this suite of educational resources variously target health service providers and Aboriginal client groups. Education resources were developed in two forms: Yolŋu language resources for Yolŋu client and community groups, and English language resources that can be used in cross-cultural settings. PAR discussions, reflections and activities were also videotaped as a means of documenting and reviewing the research process. Yolŋu discussions were recorded on video and later transcribed into Yolŋu Matha and English text.

A digital file management system, or project database, was developed to preserve the English and Yolŋu language interactions and PAR reflections that were originally recorded on videotape. Project participants involved in developing *wititj* (*Lit. olive python*), the name Yolŋu participants gave to the database, envisage that it will be an ongoing resource for project participants and future research. The multimedia consultant, who worked with team members to develop this resource, highlighted its potential.

> **I guess as people become more familiar with the medium there will be some interesting directions that it takes, and we don't know what they're going to be, but it's good to be as flexible as possible so that those different things can happen…Use the technology but just let it be manipulated a little bit, and let people play with it, and change it, put in their own words in their own languages and be able to search through them. We've got a lot of work to do in that area…We can have the file management system set up in such a way that people can delete items, change the names of things, move the order of the items around, create their own presentations from some of the items in there. Should there be a conference coming up…they can simply go and piece things together into their own little arrangement and push it out into something that might be functional for the time. So that's probably one of the more important aspects of (the database).**

Data sources included audiotapes of the informed consent process, and videotaped interviews and interactions between project participants with specific expertise (medical, cultural, linguistic, multimedia), including experienced Yolŋu interpreters. Film footage of wider discussions within the action research teams and of consultations in remote communities has also been archived. Relevant text documents and still photographs are included in the database. The digital file management system holds a record of the multiple perspectives of project participants in their own languages and idioms.

## Working across languages and cultures

Many participants were experienced in working across cultures and languages and in collaborative group processes. Activities were taped on video to document action research and allow for feedback, thereby being inclusive of Yolŋu participants and minimising text-intensive work. The needs and priorities of patients and family members had to be respected. There were times when Yolŋu participants had social and cultural obligations that took them away from the research project. Alternative ways of working, flexible hours and diverse locations were used to accommodate both Yolŋu and Balanda priorities and convenience.

A further challenge for the health professionals and consultant researchers was to find the time and commitment to engage with Yolŋu research participants to develop relationships of mutual respect as a foundation for devolving control and developing more effective communication and education practices. A Yolŋu interpreter highlighted the problem and the potential solution as evident in staff–patient and interpreter–interpreter-mentor relationships at NRU.

> **In that way, there should be Yolŋu and Balanda working together ga (and) listening to each other so…their communication at renal will get right with the patients. That's how nhakun (like), we did this true story so that people can see Balanda ga (and) Yolŋu way…so that Balanda and Yolŋu work together. Not just Balanda on high ga (and) Yolŋu on low, yaka (no), together, equal.**

Participants found working in two or more languages and world views was time-consuming and tiring. Interpretation, translation and transcription, although core project activities, were not sufficiently accounted for in the project plan and budget. There was an allocation in the budget for Yolŋu consultants, which enabled the project to engage registered Yolŋu interpreters and translators on AIS rates of pay.

The CDU linguist and the ARDS consultant, who was employed at RDH as an interpreter-mentor, provided in-kind support to translation and transcription activities. The linguist also engaged students enrolled at CDU in Yolŋu language and culture studies in some of the Yolŋu Matha transcription. The facilitator had the task of transcribing videotapes of the PAR reflections of the project management team and key members of the action teams. An important research finding was that considerable time and resources were allocated to work in interpreting, translating and transcription processes.

## Continuity in participation

Throughout the long-term research project, and due to the nature of working in the NT where there is high population mobility, there was significant changeover in participating health staff, which was a recurrent challenge to continuity in PAR. Over time, three nephrologists were involved in project management and leadership of Action Team A. In addition to their coming into and leaving the project, when they were participating, the nephrologists' responsibilities in clinical care at NRU and the renal ward at RDH impacted on their ability to make a sustained contribution.

The person holding the CNM position at NRU changed four times in the timeframe of STTS2 and, each time the incoming CNM was introduced into the research project, inevitably there was some loss of continuity in PAR. On the positive side, one former CNM remained involved in the project and joined the management team in her new role as NT Renal Services Development Officer. Another former CNM at NRU took up new responsibilities in training patients and their 'buddies' for self-care HDD and managing the repatriation process. In this new role she continued to participate in the PAR project.

The necessity to regroup and refocus the action teams absorbed energy and time. By contrast, there was relative stability in project management. The consultant in intercultural communication, who had worked on both stages of the project, commented on the perseverance of health staff in the long-term project.

> **We've just been really lucky to have the sort of service provider…I suppose it's sort of self-selecting, isn't it? People get involved who are highly committed, you don't even engage in a research project like this unless you are highly committed. You know, like there are a lot of people who are working in health who desperately want to improve what they are doing. And Stage 1 helped to sensitise people to the fact that what they are doing is much more seriously inadequate than they may have realised. And I think that's good. I mean, that's what we needed to do.**

Equally important has been the commitment of the principal Yolŋu researcher and a core group of Yolŋu research participants including interpreters, patients and family and community members. However, the project did expose two separate limitations, one relating to payment of Yolŋu researchers within the research framework, and the other relating to effective use of Aboriginal interpreters in health services.

## Valuing Aboriginal researchers and Aboriginal interpreters

The payment of Yolŋu consultants remained problematic within the research timeframe. Yolŋu participants who were interpreters and translators were paid on AIS contracts, whereas patients, family and community members, who were not registered with AIS, were paid on CDU casual researcher contracts. This meant that Yolŋu researchers received different rates of pay for the same time commitment, which aroused considerable confusion and discontent among Yolŋu participants. The principal Yolŋu researcher reflected on the problem.

> **Lots of us Yolŋu are registered over there with the interpreter service. AIS pays us. And many others here are paid by the university, leading to us to be confused. We are fed up with this (system), we also think about withdrawing. Only I thought that way, no, I am the Yolŋu who started this work, and later I called in many other Yolŋu. I won't do that, I won't show that unhealthy (attitude) to the many other, that's what I thought. So I am still working here with the interpreter service, um no, here with *Sharing the true stories*. I am still standing right here, here with this same work, so that I can assist other Yolŋu, so that I can show my people.**

Protocols and line of management for processing the payment of Yolŋu participants on casual contracts, and invoices based on timesheets, proved to be unwieldy and resulted in problems in timeliness of pay. These problems raise serious issues of equity that need to be addressed when research projects involve Aboriginal participants and consultants.

While research strategies were directed towards alerting policy-makers, middle management and health staff to the need for effective use of interpreters in renal and hospital services, it became apparent that the capacity of AIS to deliver Aboriginal interpreters across the range of languages and who were experienced in health interpreting was limited. This remains the case in the current situation at NRU and RDH, in which there is significant unmet need for such interpreters.

Project management and action research teams engaged as research consultants a number of Yolŋu interpreters who lived in Darwin. These interpreters gained experience in health interpreting as a consequence of working with health staff and the interpreter-mentor. The Director of Anaesthesia at RDH noted that there is a considerable gap between demand and actualising patient–interpreter–staff interactions for a number of complex reasons.

> **I haven't seen the latest figures, but we were booking up to sixty (interpreting sessions) a month in the pre-admission clinic alone but achieving somewhere between ten and twenty. And there are actually about ten different reasons why that's not achieved. It's like so many things, that when you actually delve into it, the system is very complex and getting patient, interpreter and health professional all together at the same time is surprisingly difficult.**

As a result of the PAR process, participating Yolŋu interpreters gained experience in interpreting in renal and hospital contexts and an education in biomedical concepts. The interpreter-mentor has already begun to extend project strategies and methods by working with a newly recruited Yolŋu interpreter at the Gove District Hospital and in health staff–interpreter workshops in various locations in the NT. The project highlighted the need for more interpreter-mentors to facilitate the training and education of Aboriginal interpreters on-the-job in renal and hospital services and across the range of language and client groups.

# 7. Capacity development and research transfer

PAR is based on a capacity building theory and methodology that incorporates a cycle of reflection, evaluation, modification and action (Green *et al.* 1994; Cherry 2002; Piggot-Irvine 2003, 2004). The PAR process is designed to develop the knowledge and skills of individuals and groups to lead and participate in capacity building and constructive change within institutions and systems.

In STTS2, participants have been working together in ways that overcome differences in language, culture, knowledge, authority and power that typically shape miscommunication between health staff and Aboriginal client and community groups. The education of participating Yolŋu, and health staff and research consultants, has been continuous in the process of developing effective intercultural communication strategies, shared understandings and collaboratively developed educational resources.

Yolŋu patients and interpreters have developed a better understanding of biomedical information and the dialysis process and machine. Participating Yolŋu interpreters have developed confidence and skills in health interpreting in renal unit and hospital contexts. Health staff and project consultants have developed knowledge and skills in regard to effective communication and education across cultures and languages and multimedia technologies. Participating health staff in renal and hospital services have gained an appreciation of the need for effective intercultural communication and have developed their own communication skills and utilised Aboriginal interpreters more effectively in their work practices.

The STTS2 budget had funding identified for the development of educational resources, and payment of Yolŋu research consultants, but did not have an allocation specifically for capacity building among health staff and Aboriginal interpreters working in health. Despite the lack of a specific capacity development plan and budget line, considerable improvements in competencies in intercultural communication and health education have been reported in the research project.

There is evident need for the health system and institutions to further develop strategies and resources for capacity building, in the Aboriginal health workforce and Aboriginal interpreter workforce in health, in effective intercultural communication and education in Aboriginal health contexts. Towards the end of the research timeframe, the scheduled roll-out of HHD services across urban, rural and remote communities in the NT, and planned repatriation to their home communities of Aboriginal ESRD patients being trained in self-care HHD, has brought an urgency to the need for more effective communication and education in the NT renal services context. Further research, beyond the scope of the STTS2 project, is required to monitor the effectiveness of the education and training of Aboriginal renal patients, and their support 'buddies', in preparation for self-care HHD and following their repatriation.

The NT Renal Services Development Officer has identified the need for renal services to improve communication strategies between service providers and Aboriginal client groups by means of telecommunication technologies. This would include being able to:

> **use a telephone as a way of accessing interpreters, both for the people back in the communities and for the people who are here, dialysing in town. And I also hope we will be able to find some money…for some video conferencing that we don't put in the dialysis unit but we put it in the other clinics, or the school, or somewhere where a number of people can access it…**

There is potential for PAR methods tested in STTS2 to be transferred to further research to develop and evaluate strategies and resources required for health staff, Aboriginal interpreters and Aboriginal client groups to communicate effectively via a range of telecommunication options, between rural and remote communities and renal units and hospitals in urban centres in the NT. In the meantime, STTS2 participants have been disseminating and transferring research findings, intercultural communication strategies and educational resources in a number of ways including by:

- carrying out the project within health services, with practitioners and patients to act as communicators and champions of the findings to their peers;

- engaging with policy-makers, middle management and the public through ministerial launches of strategies and resources;

- educating the Aboriginal health workforce by means of introducing strategies and resources into existing in-service opportunities, professional development schedules and cultural awareness training programs;

- mentoring, educating and training Yolŋu interpreters within the Aboriginal interpreter workforce in health interpreting in hospital, renal unit and self-care HHD contexts;

- contributing abstracts, presentations and keynote addresses to a number of conferences and workshops at international, national and NT forums;

- consulting with and obtaining cultural validation of strategies and resources among Yolŋu client and communities groups in Darwin and in a number of Yolŋu remote communities;

- evaluating the potential transferability of the research process, strategies and resources within the framework of the NT Renal Services roll-out of satellite renal units and the option of HHD services; and

- developing and maintaining the STTS web site and project database as repositories for project findings and resources and as ongoing resources to link to related research.

A number of research transfer outcomes, including Aboriginal Interpreter Services Guidelines, have been implemented across the delivery of health care in the NT. STTS2 educational resources are being evaluated in health delivery and staff in-service contexts in Darwin, Nhulunbuy and Alice Springs, and in a number of remote communities in north and central Australia. Intercultural communication strategies and educational resources, and related links, are being continuously updated on the STTS web site and therefore are widely accessible via the internet. For further evidence of STTS2 outcomes in regard to research dissemination and transfer, see Appendix 1.

# 8. Conclusions

In Stage 2 of *Sharing the true stories*, participating researchers, including policy-makers, service providers, client and community groups, and consultant researchers have engaged in dialogue and collaborative action across languages and cultures, responsibilities and expertise, urban centre and remote communities, renal units and hospital, and government sectors of health and community development.

STTS participants have engaged at policy and middle management levels to leverage institutional and system-wide change. The research project has contributed strategies and resources for building capacity in the Aboriginal health workforce and Aboriginal interpreter workforce in health towards more effective communicative and educative practices between health care providers and Aboriginal client and community groups. Participating Yolŋu patients, and family and community members, have benefited from more effective communication, better understanding and more control in decision-making in renal care, particularly at NRU and in the context of community consultations and patient and support 'buddy' training in self-care HHD.

The strategies for improving communication that are identified and addressed in this project go beyond the solutions often proposed in the past, which target only one component of the problem, such as communication practice within the medical encounter. First, a 'solution' to improving intercultural communication in Aboriginal health is to institutionalise effective use of Aboriginal interpreters in and beyond the medical encounter. Second, the research also found that health staff, interpreters, patients and members of their families and communities benefited from educational opportunities and resources that led to more effective communication and shared knowledge in Aboriginal health. Third, Aboriginal patients, families and communities gain more control in their health care by participating in the development of strategies and resources to improve intercultural communication and education in Aboriginal health. Finally, the community consultations and training and education of patients and their supporting kin in self-care HHD has been a significant initiative to improve communication, share knowledge and shift power between health service providers and Aboriginal client and community groups.

Although early indications are that there is a commitment by individuals and, to some extent, institutions to improve the structures and systems that inhibit effective communication at NRU and RDH, whether or not such changes become sustainable depends not just on compelling research findings but also on political will and resource commitment. Humphery, Weeramanthri and Fitz (2001:106) have suggested that many health professionals see the institutional practices contributing to the poor standards of Aboriginal health as '*given* rather than *contestable*'. This project has shown that there is potential to transform such practices if and when health staff, health researchers and Aboriginal interpreters, patients and their supporting family and community members collaborate in bringing about change. The principal Yolŋu researcher concluded that the STTS project has highlighted the potential of the health workforce to work with Aboriginal client and community groups to share knowledge and decision-making, in order to address the imperative of improving communication in Aboriginal health care.

> **Napurr li ga yolŋukurr waŋanhamirr ga walal li ga nhakun balandakurr waŋanhamirr ga yalala napurr nhakun lakaranhamirrdja, nhaku napurr li ga waŋanhamirr, ga nhaku walal li ga waŋanhamirr. Ga nhaltjan napurr dhu ga rulwaŋdhun wark maṉdany walalaguŋ ga napurruŋ manapandja, nhaltjan yä bitjan. Ga dharrwamirr ŋuli nhakun napurr li ga guŋga'yunmirr, walal li balandayny malany guŋga'yun napurruny yolŋuny, ga napurr yolŋuyny walalany guŋga'yun balandany walalany. Yolŋuyny nhakun napurr guŋga'yun walalany balandany marr dhu ŋunha mulkurrŋur walalaŋal bu'arryun yä bitjan, ga napurruŋal yaka dhu ga wititjwititjthirr ŋorra, yaka dhu waŋganydhu or märrmay buku-moma ŋäma.**

> **We talk together in Yolŋu language, and they talk together in English, and later we tell each other what we are talking about, and what they are talking about. And how we can put together the two works, (the thoughts) from them and (the thoughts) from us, how (to do it). And many times we help each other. The Balanda mob help us, and we Yolŋu help them, the Balanda. We Yolŋu help them, the Balanda. So that in their heads it becomes clear, like that, and for us it must not be confused. Not one or two must misunderstand.**

# Appendix 1: Milestones and achievements

## Engaging policy-makers and the community

- The public meeting at the Mirambeena Resort in Darwin on 28 February 2003 to communicate information about Stage 1 findings and Stage 2 strategies, and to invite Yolŋu participation in the second stage of research.

- The Minister for Health, the Hon. Dr Peter Toyne, MLA, opened the self-care HDD training facility and launched the *Sharing the true stories* web site at a public event at NRU on 31 May 2004 (CDU 2004a).

- The Minister for Health, the Hon. Dr. Peter Toyne, MLA, in company with the Minister for Community Development, the Hon. Mr John Ah Kit, MLA, launched the educational resource *Getting serious about communication in Aboriginal health* at RDH on 18 August 2004. Yolŋu participants signalled the importance of communication in health by performing a message-stick ceremony in the hospital foyer (CDU 2004b).

- The Minister for Employment, Education and Training, the Hon. Syd Stirling, MLA, on behalf of the Minister for Health, the Hon. Dr Peter Toyne, MLA, opened the Galiwin'ku Self-Care Dialysis Facility at the Galiwin'ku Community, Elcho Island, on 13 May 2005. A *Sharing the true stories* resource, a DVD in Yolŋu language about the dialysis machine and self-care process, was released on this occasion (CDU 2005).

## Educating the health workforce and Aboriginal interpreter workforce in health

- At RDH, sessions on effective use of Aboriginal interpreters have been introduced into a number of in-service forums, including within the 'Grand Rounds' for health professionals and staff orientation programs.

- Aboriginal Cultural Awareness Program sessions have been conducted at RDH and Gove District Hospital, which have included STTS2 presentations by health staff and Yolŋu interpreters on effective use of Aboriginal interpreters.

- At NRU, a number of staff in-service sessions have been conducted with project participants presenting STTS1 findings about the extent of miscommunication in renal care and STTS2 strategies and resources to improve communication and education in renal services.

- Project participants held discussions with health staff, AIS staff, and Aboriginal client and community groups to promote effective communication and education in Aboriginal health in Alice Springs at the Flynn Drive dialysis unit, Alice Springs Hospital, and with renal clients and families from the Kintore community, May 2005.

- A one-day workshop for Kakadu health staff on 'Cross-cultural communication and STTS2 educational resources' was conducted by project participants at the Environmental Research Institute of the Supervising Scientist Conference Centre, Jabiru, 22 June 2005.

- A 'Health interpreting workshop' was held by project participants at Katherine Language Centre, 30 June 2005.

- A presentation was made to nursing staff on '*Sharing the true stories* and intercultural communication' at Katherine District Hospital, 1 July 2005.

- The 2004 Churchill Fellowship recipient in the Northern Territory, a dietician at NRU, will use her experience in working within the *Sharing the true stories* project and similar methodology to plan and conduct her Fellowship project involving renal dieticians and health workers interacting with Indigenous clients. The project will involve research in selected international contexts in 2005.

## Guidelines and resources

- The Aboriginal Interpreter Services Guidelines (research transfer with AIS) were launched, together with the STTS web site and related resources, on 31 May 2004 at NRU and subsequently promoted and disseminated widely across north and Central Australia.

- A new education support program in print, video, CD-Rom, DVD, and web site formats, which has been developed and continues to be evaluated and updated, includes:

  - www.sharingtruestories.com;

  - *Getting serious about communication in Aboriginal health*, an English-language DVD that promotes the effective use of Aboriginal interpreters in the hospital setting;

  - *Räl manapanmirr limurr djäma: Working together*, an English- and Yolŋu-language DVD that utilises a cultural metaphor for the haemodialysis process and for health staff and Aboriginal client groups working together;

  - *Sharing the true stories: Improving communication in Indigenous health care*. Report/Stage 1, a Yolŋu-language DVD for Yolŋu client and community groups;

  - *Dialysis machine story*, a Yolŋu-language DVD for Yolŋu client and community groups;

  - illustrated plain-English texts of the circulatory and respiratory systems, and of kidney function, which Yolŋu call the heart, lung, and kidney 'stories'; and

  - a digital file management system that stores and allows updates of PAR reflections and resources.

## Publications and presentations

- *MJA*/Wyeth award article based on Stage 1 findings:
  Cass, A., Lowell, A., Christie, M., Snelling, P.L., Flack, M., Marrnganyin, B. and Brown, I. 2002, 'Sharing the true stories: Improving communication between Aboriginal patients and healthcare workers', *Medical Journal of Australia*, 176:466–470.

- Abstract and presentation titled 'Sharing the true stories: Improving intercultural communication in renal services', submitted by Flack, M., Patel, B., Trotter, B., Warrayak, A., Marrnganyin, B., Ritchie, T. and Coulehan, K. (presenter underlined) at *The 12th International Congress on Nutrition and Metabolism in Renal Disease, Padova–Venice, 19–22 June* 2004.

- Abstract and presentation titled 'Sharing the true stories: Improving communication and shifting power in Aboriginal health', submitted by Flack, M., Patel, B., Trotter, B., Warrayak, A., Guyula, H., Marrnganyin, B., Mitchell, A. and Coulehan, K. (presenters underlined) at *The Dreaming Together Experience: The 6th international diabetes and blindness conference for Indigenous peoples*, Cairns, 7–10 September 2004.

- Keynote presentation by Betty Marrnganyin, Phyllis Batumbil and Anne Lowell, titled 'Sharing the true stories: Improving communication between health staff and their Aboriginal patients', at the *National Services for Australian Rural and Remote Allied Health (SARRAH) Conference*, Alice Springs, 26–28 August 2004.

- Workshop presentation by Betty Marrnganyin, Phyllis Batumbil and Anne Lowell, titled 'Paddling in the same canoe: Working together to improve communication in Indigenous health care', at the *National SARRAH Conference*, Alice Springs, 26–28 August 2004.

- *Sharing the true stories* presentation, 'Action research: A case study of working with northeast Arnhem Land communities', presented by Marrnganyin, B., Guyula, H. and Patel, B. at the *Action learning, Action research and project management conference*, Darwin, August 2004.

- *Sharing the true stories* presentation, 'Räl manapanmirr limurr djäma: Working together', a research case study by Guyula, H., Gaypirra, W. and Patel, B., at the *Indigenous Research Workshop*, Centre for Remote Health, Alice Springs in association with School of Australian Indigenous Knowledge Systems, CDU, 27 September–1 October 2004.

- '*Sharing the true stories*, Stage 2, Participatory Action Research', presentation by Kerin Coulehan at the *Indigenous Research Workshop*, Centre for Remote Health, Alice Springs in association with School of Australian Indigenous Knowledge Systems, CDU, 27 September–1 October 2004.

- 'Communicating across cultures', presentation by Bhavini Patel at the *4th Biennial Society of Hospital Pharmacists of Australia (SHPA) Conference*, Sydney, 29–31 October 2004.

- '*Sharing the true stories*: The role of the interpreter', presentation by Betty Marrnganyin and Helen Guyula, at the *NT Interpreters Conference*, Batchelor Institute of Indigenous Tertiary Education, Batchelor, NT, 25 June 2005.

- 'Health training for Aboriginal interpreters: Using story methodology', presentation by Alice Mitchell, *NT Interpreters Conference*, Batchelor Institute of Indigenous Tertiary Education, Batchelor, NT, 25 June 2005.

# List of shortened forms

AIS        Aboriginal Interpreter Service

ARDS       Aboriginal Resource and Development Services

CDU        Charles Darwin University

CD-Rom     Compact Disc Read Only Memory

CNM        Clinical Nurse Manager

CRCAH      Cooperative Research Centre for Aboriginal Health

DHCS       Department of Health and Community Services

DVD        Digital Video Disc, also known as Digital Versatile Disc

ESRD       End Stage Renal Disease

HHD        Home Haemodialysis

MLA        Member of the Legislative Assembly

NT         Northern Territory

NRU        Nightcliff Renal Unit

PAR        Participatory Action Research

RDH        Royal Darwin Hospital

SARRAH     Services for Australian Rural and Remote Allied Health

STTS       Sharing The True Stories

STTS1      Sharing the true stories, Stage 1

STTS2      Sharing the true stories, Stage 2

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# Sharing the true stories resources

stts is a collaboration of a multidisciplinary group of participants who have been working together to identify the gaps in communication in the health care setting and implement strategies to help bridge these gaps.

## dvds

### stage 1 report

a series of film clips providing a summary of stage 1 of the stts project

suitable for all members of the Yolŋu community
Yolŋu *language, no subtitles*

### working together

film about dialysis and the metaphor of cycad bread processes and production

suitable for all members of the Yolŋu community, patients with early and end stage kidney disease and for health staff
*english and* Yolŋu *language with subtitles*

### story about dialysis

a conversation around the workings of a haemodialysis machine

suitable for all members of the Yolŋu community, patients and family members with early and end stage kidney disease
Yolŋu *language, no subtitles*

### getting serious about communication

film about using interpreters; exemplifying real situations and acted by health staff and interpreters

suitable for policy makers, health staff and interpreters
*english and* Yolŋu *language*

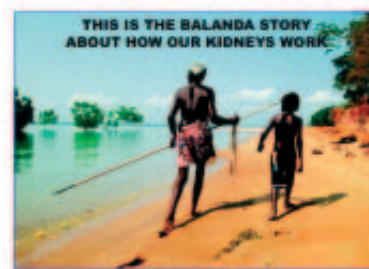Sharing the true stories resources continued ...

## www.sharingtruestories.com



website displays information and media objects from the stts project as well as useful links.

suitable for Yolŋu community members, health staff and the broader community
*english and* Yolŋu *language*

## picture books (conversation starters)



a series of picture books describing how the current biomedical model understands the functioning of our bodies. these have been created to provide visual resources to aid in developing shared understandings about pathology and treatment options

suitable for use in all health education settings
*plain english*

## wititj media management system
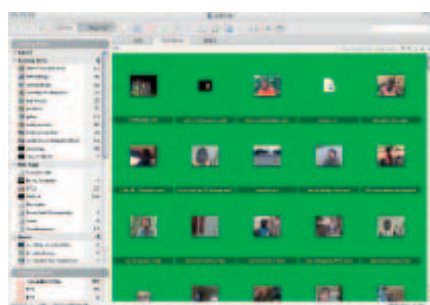


*wititj (olive python)* is the name given to the file management system being used by stts participants. wititj allows multiple participants to organise media and meta-data according to their own relationships and requirements

suitable for participants of the stts project
*english and* Yolŋu *languages with subtitles*

## stage 2 report



a series of film clips displaying the reflections of stts project participants using selected media from wititj. the use of audio-visual media in this report is in keeping with the nature of the recommendations of the first stage of the project

suitable for Yolŋu community members, health staff and the broader community
*english and* Yolŋu *languages with subtitles*

# sharing the true storie stories resources

## order form—prices on application

quantity

### stage 1 report dvd

a series of film clips providing a summary of stage 1 of the stts project

Yolŋu *language, no subtitles*

### working together dvd

film about dialysis and the metaphor of cycad bread processes and production

*english and* Yolŋu *language with subtitles*

### story about dialysis dvd

a conversation around the workings of a haemodialysis machine

Yolŋu *language, no subtitles*

### getting serious about communication dvd

film about using interpreters; exemplifying real situations and acted by health staff and interpreters

*english and* Yolŋu *language*

### picture books (conversation starters)

a series of picture books describing how the current biomedical model understands the functioning of our bodies. these have been created to provide visual resources to aid in developing shared understandings about pathology and treatment options

*plain english*

### stage 2 report dvd

a series of film clips displaying the reflections of stts project participants using selected media from wititj. the use of audio-visual media in this report is in keeping with the nature of the recommendations of the first stage of the project

*english and* Yolŋu *language with subtitles*

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