

East Arnhemland
Client Health Education and Health Interpreting
Scoping Report and Project Proposal

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Office of Aboriginal and Torres Strait Islander Health
by Charles Darwin University

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Abbreviations

AIS	Aboriginal Interpreter Service
ACW	Aboriginal Community Worker
AHW	Aboriginal Health Worker
BIITE	Bachelor Institute of Indigenous Tertiary Education
CDU	Charles Darwin University
COPD	Chronic Obstructive Pulmonary Disease
CQI	Continuous Quality Improvement
DHF	NT Department of Health and Families
EAL	East Arnhemland
OATSIH	Office of Aboriginal and Torres Strait Islander Health
PAR	Participatory Action Research
PDCA	Plan Do Check Act
PHC	Primary Health Care
PHRG	Primary Health Care Reform Group
RAHC	Remote Area Health Corps
WHO	World Health Organisation

Part 1 Scoping Study Report

1.1 Introduction

This scoping study has been commissioned from *Charles Darwin University (CDU)* by the *Office of Aboriginal and Torres Strait Islander Health (OATSIH)*. It scopes out a potential project for improving and supporting the work of health education and interpreting in East Arnhemland (EAL); specifically in Milingimbi, Ramingining, Gapuwiyak, Galiwin'ku, Yirrkala, Nhulunbuy, Angurugu, Umbakumba, Numbulwar and homelands.

Researchers in the *Australian Centre for Indigenous Knowledge and Education* (previously the School of Australian Indigenous Knowledge Systems) and the *School of Education* at CDU have experience in health communication research and collaborative and Indigenous research methodologies. All members of the project team have lived and worked in the East Arnhem region. Current work includes the development of multimedia resources for health literacy and interpreting around COPD (Chronic Obstructive Pulmonary Disease). Some team members have worked previously with the Aboriginal Interpreter Service (AIS) on training and accreditation of interpreters in Yolŋu languages.

An ethics clearance was obtained from the CDU Human Research Ethics Committee to talk to people about this project plan. Should the project be approved for implementation, an update of the ethics clearance would be sought.

This document presents the findings of the scoping study in Part 1: Scoping Report, followed by Part 2: Project Proposal.

1.2 Methodology for this Scoping Study

Literature review

A wide range of literature was reviewed including global, national and Northern Territory health and chronic disease reports, policies and plans; medical, health literacy and communications research.

Multimedia resource review

A number of visual and multimedia resources for medical and educational use were reviewed in relation to this project (refer Appendix).



<http://www.cdu.edu.au/centres/hl/>

Website and brochure

A website (<http://www.cdu.edu.au/centres/hl/>) and brochure about the potential project and scoping study were produced to introduce, publicise and invite people to participate in the online survey and project. A link to the website and brochures were distributed to health centres, and to key organisations and personnel in East Arnhemland and the Northern Territory. Due to the short timeframe, around 20 Indigenous health workers were also personally contacted and interviewed in their own languages.

Online survey

An online survey was developed that asked for respondents to rate their response to each of the following five statements (1 – 5) as: very important, important, not really important, or unnecessary at this stage, and space was provided for people to write comments and to answer the final question (6):

1. More local training for Aboriginal Health Workers, Community Workers and families about the biomedical story of the body, sickness and treatment
2. More local training for non-Aboriginal staff in health communication and the use of interpreters
3. More interpreters available to work in health care (clinics, community, homes, hospitals etc)
4. Better communication practices in Health Care (clinics, community, people's houses, hospitals, etc)
5. Recruiting and training more people for health work and interpreting
6. What other areas should be investigated and improved if we are going to achieve better client health education and health interpreting?

People could complete the survey on their own or together with others, and some Yolŋu respondents were interviewed by Yolŋu in language over the phone. The survey asked for names and contact details of respondents (not obligatory) and names of other people considered important to contact about this project. A total of 52 people responded to the survey from health organisations and communities (refer Appendix).

Stakeholder interviews

More in depth interviews and conversations were conducted with managers and key representatives from: NT Department of Health And Families (DHF), the AIS, Menzies School of Health, Miwatj Health (Gove and Galiwin'ku), Laynhapuy Health, Marthakal Health, and with medical researchers including Yolŋu researchers from the 'Healthy Breathing and Heart' project (refer Appendix).

1.3 Findings

From the stakeholder interviews, survey results and literature review, there was widespread agreement as to the key factors directly related to improving client health education and interpretation in East Arnhemland. These have been classified into the following areas:

- Policy and service delivery environment
- Chronic conditions prevention and management
- Client-centred and self-managed health care
- Health care teams
- Cultural security
- Health literacy
- Health literacy resources
- Health interpreters
- Continuous Quality Improvement (CQI)

The *East Arnhemland Client Health Education and Interpreting Survey Analysis* can be found on the project website (<http://www.cdu.edu.au/centres/hl/>).

Policy and service delivery environment

The project will be implemented in a very complex health services delivery environment: nine major locations mostly remote Aboriginal communities and many homeland centres, a complex arrangement of programs with providers within the Aboriginal Medical Services and NT Department of Health and Families, a large range of professional roles, a diversity of languages, and a mounting epidemic of preventable chronic disease.

Chronic disease prevention and management

There is widespread agreement that the rapid rise in the prevalence of chronic conditions is impacting on health and social systems nationally and internationally and will increase over the coming decades. The indisputable links between health, chronic disease and economic development make this an even greater concern for developing countries and disadvantaged population groups. By 2020 developing countries can expect 80% of their disease burden to come from chronic conditions. The resulting low health outcomes will be a very high cost to society, governments and families (WHO, 2002). The prevalence of chronic conditions in the NT reflects this national trend with a current crisis in Aboriginal communities.

The *World Health Organisation* (2002) argues that chronic conditions can no longer be viewed as discrete health problems, and that a paradigm shift in health care from 'an acute, episodic health care model' to a chronic disease prevention and management model at macro (government and policy), meso (health and community organisation) and micro (client (patient) interaction) levels is required.

The Australian and NT Government commitments to 'closing the gap' and the primary health reform process currently being implemented in the NT have provided significant funding increases both for the Aboriginal community-controlled health sector and NT government health services. The aim is that all Aboriginal people have access to a relatively standard suite of primary health care services including those related to chronic disease care.

Through the *Healthy for Life* program, OATSIH provides funding for over 80 primary health care services, to improve the quality of child and maternal health services, chronic disease care, and the capacity of the Indigenous health. A major focus of the program is service review and continuous quality improvement.

The *NT Chronic Conditions Prevention and Management Strategy 2010 – 2020 (NT Strategy)* together with policies of community health care organisations provide opportunities for improving programs for Aboriginal people in urban and remote areas related to the prevention and management of chronic conditions, and will increase the number of practitioners as well as increasing Aboriginal community control of health services. The NT Strategy aims "to improve the health and well being of all Territorians by reducing the incidence and impact of chronic conditions". The strategy focuses on the following conditions:

- Cardiovascular disease (ischaemic heart disease, heart failure, hypertension, stroke)
- Rheumatic heart disease
- Type 2 diabetes
- Chronic airways disease (cmicro/macro albuminuria, decreased GFR)
- Chronic kidney/renal disease
- Chronic mental illness (depression anxiety, psychoses)
- Cancer (those cancers associated with the common risk factors for other chronic conditions)

Most chronic conditions and their associated complications are preventable. Infants' failure to thrive is the first preventable precursor of chronic disease, and child-maternal health is another key area is becoming an equally important health care focus in Aboriginal communities.

There was widespread agreement in literature and stakeholder interviews that:

- chronic disease care involves a focus on prevention with the need for regular scheduled contact over time for disease monitoring – best undertaken by practitioners with a long term relationship with patients/families
- consultations ideally are family-centred focusing on self-management and health literacy – building confidence for patients and their families to manage their chronic disease
- the patient having ongoing symptoms (sore legs for example in diabetes) are in a sense the experts in the progression of their disease and their family shares in their understanding and treatment of those symptoms
- the work of maintaining treatment for chronic diseases is not technically difficult (i.e. it doesn't require a high level of numeracy or literacy training) but is time consuming, and requires some key background knowledge and communication practices and a relationship of trust with clients and their families
- with the increased turnover of non-Aboriginal staff in remote health services, it makes good sense for Aboriginal health workers, community workers and their families to become increasingly informed and competent in chronic disease care
- there is general concern about communication practices between both Aboriginal and non-Aboriginal health personnel and Aboriginal clients around health issues; and what is perceived to be a low level of health literacy and biomedical understanding among Aboriginal clients, as well as among interpreters and some trained Aboriginal health personnel

Client-centred and self-managed health care

Client self-management is a key goal of chronic disease care. The *WHO Innovative Care for Chronic Conditions (ICCC) Framework* and *NT Strategy* place the client (patient) and family at the centre of health care. The client is no longer viewed as an inactive, passive recipient of health care, but rather as an active partner or health producer. This elevates the roles of clients and their families, and recognises that with the appropriate knowledge and support, they are in the position to most effectively self-manage their chronic disease/s. Accordingly, clients need to be well informed about their chronic condition; enabled to access and adhere to medical treatment programs and long-term therapies and maintain healthy behaviours; prepared with skills to manage their conditions in the context of their extended family; and well supported by health care teams and their communities.

Improving the client journey

In the context of this project the term 'client journey' refers to a process of 'mapping' the client's journey through the health care system, and incorporates the individual's lived experience and views of health care (Baron, 2009). Developing a clear understanding of the client journey is fundamental to improving the health system, the prevention and management of chronic conditions and quality of life. There are a number of different methods commonly used to research and map the client journey, including 'process mapping', that have been shown to improve health care practices and systems by focusing on the experience of the client rather than the clinician; supporting health care team building; identifying issues, barriers and best practice; increasing patient, and staff morale and motivation; and collecting evidence to support changes in the service/environment.

Health care teams

Ongoing changes in the health workforce towards regionalisation and community control, and from a medical model to a primary health care model of health care delivery and management involve changes to roles and practices of existing personnel, e.g. Aboriginal Health Workers (AHWs), and the development of new positions such as Aboriginal Community Workers (ACWs), Aboriginal Hearing Workers, Mental Health Workers, Public Health Coordinators and Area Service Managers as well as expanding the work of the Aboriginal Interpreter Service (AIS).

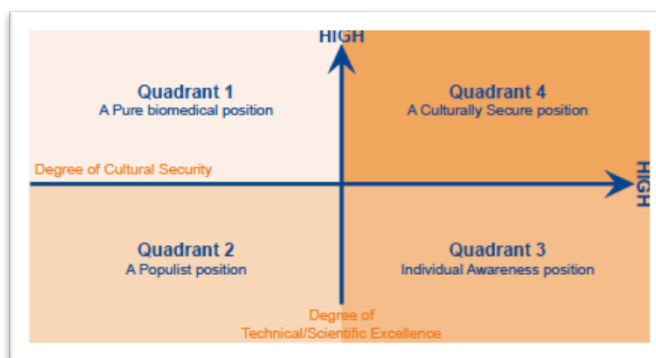
Rather than a physician or clinic-dominated model, the new paradigm requires a flattened hierarchy and the development of 'health care teams' made up of clients and family members, together with AHWs, ACWs, Clinic Managers, doctors, nurses and specialists, in which each member of the team is valued for his or her unique experience and skills.

Responses to both surveys and interviews placed foremost importance on the continuing education and training of health team personnel in order for them to develop the specialised knowledge and skills related to the emphasis on chronic disease care and self-management that include: biomedical understanding of the conditions and complications, and their prevention and treatment collaborative/cooperative working skills; communication abilities and cross-cultural interpreting; client education; behaviour change techniques; and counselling skills. Further exploration of the barriers to health education and health was stressed.

Communication and coordination across primary, secondary and tertiary levels of health care services and providers within organisations; and between the different contexts, services and organisations in health, enhances the collective knowledge, information and skills of multiple health care workers.

Cultural security

The NT Department of Health and Community Services enacted a 'Systems Performance and Aboriginal Cultural Security Policy' in 2007 that declares, "Cultural Security seeks to ensure that the construct and delivery of health and community services functions occurs within a framework that sensitively unites Aboriginal cultural rights, views and values and the science of human services ... Cultural Security will require a shift in the system's thinking from just knowing and understanding to a focus on how we behave and provide services ... Cultural Security means that the health and community services system will come to understand far more clearly than at present what Aboriginal people value and how we can work with these values to achieve better services, outcomes and more satisfied clients."



The objective of the *Cultural Security Policy* is to move the system to 'quadrant 4 of the cultural security matrix: where culture, science, policy and workplace behaviours are well aligned. Good technical care is embedded with cultural values to produce an enriched service environment.

Most survey respondents feel that local cross-cultural awareness education, and 'Two-Ways or Both-Ways' learning, as well as training in how to work with interpreters is very important for non-Aboriginal health staff, especially new staff in order for meaningful and respectful communication with Aboriginal staff and clients, and for the development of good working relationships. Several Aboriginal respondents also feel it is important that non-Aboriginal staff learn to speak the local language. It was also felt that non-Aboriginal staff should be recruited for "the right reasons, not money" and provided with cross-cultural and medical training, mentoring and support specifically related to working in remote communities.

Health literacy

The project will work with a definition of health literacy as:

"the capacity to build and generate shared understandings about health, treatment and health services. This definition focuses upon both knowledge and the structures and processes through which agreed understandings and agreed ways forward are negotiated, produced and reproduced".

From our preliminary research, we suggest that "health literacy" needs to be defined in terms of both what Aboriginal clients know about the biomedical understandings of their health and sickness, and also in terms of the services, systems and resources which are available for them to access help in discussions over health and sickness, and their ability to access and use those systems. In this way we are talking about "*health services literacy*" when we use the short-hand health literacy.

The term '*both ways health literacy*' could be used to emphasise the importance of valuing both biomedical and Aboriginal knowledges', structures and processes in relation to developing shared understanding about human being, the body, pathology, sickness and health (wellness). The need to develop both ways health literacy obviously applies to both Aboriginal and non-Aboriginal health care workers (specialists, doctors, nurses, health care workers, community workers and volunteers), as well as to clients. A focus on 'both ways' health literacy could assist in promoting cultural security.

Nearly everyone in the survey and interviews agree that it is very important that all people working in the health area in Aboriginal communities have training about the biomedical story, and an understanding of specific biomedical language and concepts. However, many people also feel it is just as important for both Aboriginal and non-Aboriginal people to have an understanding of the local Aboriginal language and concepts of the body and health. It was noted that AHWs need more and ongoing health and interpreter training.

Building knowledge through collaborative conversation and shared understanding

'*Sharing the True Stories*', a project in which two of the current team were involved, highlights that simply 'translating or transcribing' biomedical ideas and existing resources from English to an Aboriginal language does little to improve health literacy, and in fact this approach may actually decrease and inhibit health literacy. On the other hand conversations about health ideas involving groups of Aboriginal people of the same language groups, in comfortable settings, where the different services (nutrition, medication, patient education etc) were conducted together, enabled people to share their experiences and to build knowledge collaboratively.

Findings from the interviews and the survey also emphasise the value and importance of group work and discussions family meetings; and shared stories and responsibility for health care.

Health literacy resources

There was general agreement that it is important to have appropriate and simple [clear] health education resources specifically designed for Aboriginal clients in communities. Although a wide range of resources, e.g. flip charts and online biomedical animations, are already available to health practitioners to support chronic disease management in East Arnhemland, it seems that these resources are generally not in active or highly productive use in building shared understandings in health contexts.

Our previous work evaluating medical interpreting resources, and our current investigation indicates that this poor uptake is due in part due to the following:

- resources are often designed to contain and convey information (i.e. they are designed to be didactic), rather than to promote and contextualise the various discussions and dialogue around which health literacy is built (i.e. to be 'generative'). It is the discussions and narratives that are generated outside of the resource itself in the context of the client and family, which provide the basic building blocks for health literacy. We believe this constitutes a significant departure from conventional understandings of health literacy resources.
- resources lack flexibility: they demand a particular form of engagement – generally passive viewing and listening – rather than inviting the building of shared understandings, agreements and plans for care, thereby supporting client self-management

- resource design has not been specifically targeted at the particular contexts in which building agreement (and consent) in East Arnhemland fall down, e.g. our previous work on evaluation of COPD health literacy resources has shown that the western biomedical focus upon the microscopic (cell morphology, blood components, gas exchange...) to be very difficult to represent graphically to non-English speakers, and not particularly productive in the conversations making agreement over ways forward in the management of particular cases of COPD
- resources often include and assume western conventions of representation (scale, three dimensionality, movement etc, as well as colours, e.g. blue and red for oxygenation, which are not part of the visual culture of many clients
- insufficient attention paid to the holistic and aesthetic quality and integrity of the experience of the resources and of the contexts of their use
- resources often are developed without the involvement of staff or community, and do not come with professional development or training on their use. In other words it is assumed that staff, including AHW, community workers or allied health staff, have the competency to use the resources, and/or that new resources fit into existing processes utilised in primary health care settings
- resources such as flipcharts, DVDs are distributed once they designed, but not followed up on. Nobody has responsibility for the maintenance, update or storage. With large staff turnover the resources are often lost
- resources are often not part of an integrated overall approach

Better visual resources charts, posters and multimedia resources DVD's that can be incorporated into discussions (individual and group) are felt to be the most useful. Books and models are felt to have more limited use. Involvement of Aboriginal people in the creation of resources to meet local needs was also seen as important. Multimedia resources could also be developed for cross-cultural awareness and training; to assist with the recruitment, orientation and induction of new staff.

Resources we reviewed that were more successful facilitating communication and shared understanding, i.e. generating dialogue were:

- user-friendly
- interactive and 'intuitive'
- oriented and contextualised the user
- had multiple layers and zoomable views of the whole body, body systems and organ function but not down to microscopic or molecular levels (too confusing)
- were tactile (e.g. felt boards and touch screens e.g. iPad)
- were aesthetically appropriate

(Refer Appendix for Resources Review).

Health Interpreters

Initial discussions with the Aboriginal Interpreter Service (AIS) indicated that qualified and registered Aboriginal interpreters are not currently being well utilised in health settings (communities, clinics, hospitals) despite there being positions and support systems in place. It seems instead that Aboriginal Health Workers, who usually don't have formal training in interpreting, are doing a lot of this work informally. This project would begin with work to improve the uptake of existing services.

The AIS have identified a need for specially trained Aboriginal health interpreters with good biomedical and ethical knowledge, and have invited the project team to work with them to develop a specific 'Health Interpreting Module' to support the training of (i) Interpreters and potential Interpreters (ii) AHWs and ACWs and (iii) Others (e.g. school leavers and family members) in health interpreting. Programs and systems that integrate the routine use of interpreters into health care teams and settings also need to be further developed.

The new NT Government '*Community Language Allowance*', may provide additional incentive for people to undergo interpreting training and formally engage in health interpreting.

Continuous Quality Improvement (CQI)

The Continuous Quality Improvement (CQI) model is widely and successfully used in health settings and projects to improve many different health care processes and outcomes. Several EAL health care services are already engaged in processes of CQI such as Plan-Do-Study-Act (PDSA), Process Mapping and Participatory Action Research (PAR). It is important for the development of health communications, literacy and interpreting resources, materials, programs, professional development and training to be embedded in CQI and 'best practice' approaches to health care. (OATSIH Healthy for Life Program; Kemmis and McTaggart (1988) & Plsek, 1995, in Graham (1995).

1.4 Conclusion

This study has found that there is widespread agreement in medical and sociological research and with experienced Aboriginal and non-Aboriginal health personnel working in remote Aboriginal communities, that:

1. More education and training is needed for Aboriginal health personnel about the biomedical story of the body, sickness and treatment of chronic conditions, and that it is very important that this takes place locally, i.e. is community-based
2. Ongoing (community-based) training about the biomedical perspective of the body, chronic conditions and health care is needed for AHWs, ACWs, health interpreters, families and clients in Aboriginal communities
3. More people, especially young people need to be attracted to work in interpreting and in the health area
4. Aboriginal Health Workers, Community Workers and Interpreters need to be trained in health interpreting, and better supported in this role; and on-Aboriginal health personnel require training in working with interpreters
5. Better communication practices are needed in all areas of health care
6. Culturally appropriate resources that support the building of shared understanding between health personnel and Aboriginal clients are lacking and needed, in particular visual and multimedia resources, together with professional development or training in their use,
7. Health communications, literacy and interpreting resources, materials, programs professional development and training need to be embedded in CQI and best practice approaches to health care.

Key constituencies that have indicated interest in participating in the project at the local service delivery level are:

Laynhapuy Health, Marthakal, Miwatj Health (Nhulunbuy, Gunyanara and Galiwin'ku), Marthakal Health, and DHF clinics at Milingimbi Gapuwiyak, Ramingining, Anurugu, Umbakumba and Numbulwar.

At the centralised governmental delivery level, which train and deploy interpreters and health (and allied health) workers, including specialists and general practice doctors and nurses interested constituencies are: AIS, BIITE, CDU and Specialist Outreach and the Remote Area Health Corps (RACH).

Part 2 Project Proposal

2.1 Goals

The preliminary research undertaken during the scoping study enabled us to identify the following goals for the project.

To work towards the improvement of health outcomes in East Arnhemland (EAL) by developing resources, materials, and training and improving services that:

1. Involve key stakeholders in the project including: clients, their families, , and health personnel
2. Are client-centred and assist clients to self-manage their chronic condition/s
3. Increase client and professional understanding of the biomedical story
4. Increase the uptake of existing services (where appropriate)
5. Promote both ways health literacy, cultural security and authentic communication
6. Promote continuous quality improvement in health care

2.2 Guiding principles

Based on the scoping study findings we propose the following guiding principles for the development of programs, processes and resources and implementation of the project:

- Generative health literacy
- Chronic condition prevention and management
- Client-centred (client self-management)
- Simplicity and synergy
- Collaboration
- Cultural security
- Continuous quality improvement

Generative health literacy

The project will work with a definition of health literacy as:

“the capacity to build and generate shared understandings about health, treatment and health services. This definition focuses upon both knowledge and the structures and processes through which agreed understandings and agreed ways forward are negotiated, produced and reproduced”.

The project values and respects both biomedical and Aboriginal knowledges', structures and processes in relation to understanding the human being, the body, pathology, sickness, health, treatment and healing practices (both-ways).

Both Aboriginal and non-Aboriginal health personnel will be invited to participate in the project; and programs, processes and resources developed through the project will examine and foster the development of cultural awareness, shared understandings and both ways, generative health literacy and health services literacy.

Chronic condition prevention and management

A major focus of EAL regional health is one of prevention and management of chronic disease in Aboriginal communities. Accordingly, this project will focus in the first instance on the development of health literacy in the context of chronic condition prevention and management.

Client-centred practice (and client self-management)

It is hoped that clients and their families will participate in the project as well as health personnel and interpreters. Appropriate methodologies such as process mapping, small group work, interviews, coaching and mentoring will be used to ensure that any programs, processes and resources that are developed enhance and improve client self-management as well as the client experience and journey.

Simplicity and synergy

We are aware of the huge complexity of health service delivery in EAL and intend to do nothing which will increase the complexity (creating or recommending more structures, new protocols, management practices etc) but work only to join up and improve the structures, roles, and practices currently at work on the ground to improve health literacy, and the capabilities and use of interpreters.

Collaboration

Through CQI methodologies, we plan to involve any people in each community who are interested and available including AHWs, ACWs, interpreters and potential interpreters, health service clients, secondary students and school leavers interested in working in health and interpreting. People who attend workshops and training sessions that are not already employed or enrolled in training will be paid for their participation out of our budget.

Planning will take place with those who coordinate and deliver training and professional development to AHWs, ACWs and AIS to identify contexts where on-the-ground health literacy work, training and collaborative planning and evaluation can take place. These contexts are expected to range from formal workshops, focus groups, trialling and training sessions to formal and informal client-family interviews and discussions around chronic disease in local languages, public health work or clinical encounters – depending upon who is interested and available, and upon scheduling and funding, and upon collective assessment of areas of greatest need.

At the same time we will work collaboratively at the community, regional (meso) and policy (macro) levels to see how the positive changes in structures and processes of engagement in health literacy can be further institutionalised within policy and organisational cultures.

Cultural security

Cultural security for the project will be partly achieved through establishing and seeking ongoing advice from a *'Project Reference Group'*. A group of people have already agreed to be the initial contacts for negotiations and implementation strategies within EAL communities. This includes a group of bilingual bicultural Yolŋu consultants as part of the Project Team.

The focus on both ways health literacy will also help to ensure cultural security.

Continuous Quality Improvement (CQI)

The development of health communications, literacy and interpreting resources, materials, programs professional development and training need to be embedded in CQI and best practice approaches to health care. For example, the project will be developed in an evaluation framework and PDSA, PAR and process mapping methodologies will be explored as appropriate methodologies to lever opportunities for collaboration and change at micro (individual and family), meso (team and organisations) and macro (policy) levels. Both quantitative and qualitative data will be collected. We are interested to take a problem-solving rather than a problem-finding approach. We're not intending to talk about what's wrong with the system, but to work to enhance what works.

2.3 Deliverables

Overview

The project will have three distinct phases, each with a set of deliverables:

Phase 1: Research and Planning (Scoping Study) – completed

Phase 2: Developing (Proof of Concepts and Prototypes)

Phase 3: Implementing and Evaluating

Deliverables in Phase 1– completed

- *Brochure*
- *Website*
- *Online survey*
- *Scoping Study Report and Project Proposal*

Deliverables in Phase 2

- *Brochure*
- *Prototype of interactive biomedical animation* relating to the human body and at least 1 chronic condition (e.g. COPD, hearing loss, type 2 diabetes)
- *Draft health literacy materials* relating to at least 1 chronic condition
- *Community Plans* for a number of EAL communities or services that have personnel and organisations committed to work on the project
- *EAL health literacy development workshops* and/or other development programs
- *Project Web site*
- *AIS health interpreting module* - initial development
- *Progress Report*

Deliverables in Phase 3

- *Working interactive biomedical animation* relating to at least 2 chronic conditions
- *Health literacy materials* relating to at least 2 chronic conditions
- *EAL community-based implementation health literacy workshops* and/or education/training program
- *Project Web site*
- *AIS health interpreting module* - implementation and further development
- *Brochure*
- *Final Report* with recommendations for ongoing Health Literacy and budget to support ongoing work for OATSIH

Detail of deliverables

Reports and brochures

A report will be written at the end of each phase to document and report on what happened. A brochure summarising the main points of the report will also be produced to provide accessible feedback for all participants.

Interactive biomedical animation

It is proposed to develop or customise an ‘interactive biomedical animation’ of the human body that will facilitate communication and shared understanding between EAL clients, families and health care personnel in relation to understanding chronic conditions, and their prevention, treatment and management.

Some features that will be explored are:

- stylised graphic biomedical representation and mapping of the body and body systems
- interactive and intuitive

- orientation and contextualisation
- multiple layers and zoomable views – whole body, body systems and organ function but not microscopic or molecular
- touchscreens
- facilitates communication and shared understanding (i.e. non-didactic (generative),
- optional/no recorded narrative sequence or text)
- aesthetically appropriate and pleasing
- extensible

In Phase Two of the project, prototypes and proof of concepts for each resource will be developed with interested clients and health care personnel in communities and health organisations. A range of options will be investigated including producing our own resource and customising an existing application or web-based product, along with the use of touchscreens.

Health literacy materials

We may also develop materials that support the biomedical animation, and facilitate shared understandings and the development of both ways health literacy around chronic condition care and management with EAL clients. We consider it important that these materials are carefully negotiated by users, so they don't fall into the same generic and didactic trap of so much that has gone before. The point is not to encapsulate a health message into the resource, but rather to develop the resources that enable good conversations around chronic disease prevention and care, and possible derived paper resources for individual clients and their families.

Health literacy workshops, education and training

The project proposes to develop and conduct community-based workshops and/or education and training to support resource development and use. This might include the following methodology and activities:

- interviews – with individuals and groups
- round table discussions
- focus groups
- process mapping (e.g. working with groups of people to look at the health literacy and communication issues arising from the experience of clients)
- review of current and emerging resources and services
- ideas about how the institutional structures and processes which address Health Literacy might be improved
- specific training of AHWs, ACWs, interpreters etc in collaboration with BIITE, CDU and the AIS
- agreeing upon ways of evaluating and measuring the success of our work

In Phase 2, this would lead to more strategic and focussed work on resources, literacy practices, and strategies to feed into Phase 3.

Project website

The project website will be further developed and used as a way of documenting the project, and communicating ideas and progress to a wider public. The project will also explore possibilities for using a web site as a resource for supporting health professionals in working with EAL clients in chronic condition prevention and management. The website will also have the new animations available for constant access and review.

AIS health interpreting module and CDU and BIITE training

The project also aims to work with AIS:

- To increase the uptake of existing services
- To develop a health literacy module for the professional development of their para-professional interpreters

- To develop and deliver user-training for non-Aboriginal health professionals using interpreters
- To assist with testing of language competency (English and local) for the Community Language Allowance, and training in practices of interpreting focussing on ethics and informed consent with a view to eventual articulation to accreditation through NAATI

And to work with the CDU and BIITE providers of Aboriginal services training:

- To collaborative over the development and delivery of the health communication parts of their course

2.4 Action Plan

It is proposed to commence working at two levels:

1. The *local services level*: we have the interest and commitment of key people at Laynhapuy Health, Marthakal, Miwatj Health (Nhulunbuy, Gunyanjara and Galiwin'ku), Marthakal Health, and DHF clinics at Milingimbi Gapuwiyak, Ramingining, Anurugu, Umbakumba and Numbulwar.
2. The *centralised governmental delivery level*: that trains and deploys interpreters, health and allied health workers including specialists and general practice doctors and nurses. This is most particularly the AIS, BIITE, CDU, Specialist Outreach and the Remote Area Health Corps (RACH), DHF, AMSANT.

Phase 1: Research and Planning (Scoping Study)

(April – June 2010)

Now completed with this submission

- Form initial Project Team
- Obtain ethics clearance
- Begin talking to potential Reference Group members
- Make contact with key organisations and personnel at both the local EAL health service delivery level and the centralised governmental delivery level to gauge interest in and support for the project
- Conduct Scoping study, preliminary project evaluation including:
 - literature review
 - resource review
 - online survey
 - stakeholder interviews
- Identify key constituencies, i.e. people and organisations interested to participate in the project including clients and family members; health personnel and organisations; and interpreters and potential interpreters interested in health interpreting
- Plan project:
 - identify goals and KPIs
 - begin developing evaluation framework
 - develop action plan with deliverables, timeframe and budget
- Produce *Scoping Study Report and Project Proposal*

Phase 2: Developing (Proof of Concepts and Prototypes)

(To be completed 3 months after receipt of funding)

- Update ethics clearance
- Engage *Reference Group*
- Develop evaluation framework and implement front-end and formative evaluation

- *Work at the local services level* with key constituencies with health personnel and organisations; and with interpreters and potential interpreters interested in health interpreting
- *EAL Visits* to identified communities and Darwin to:
 - identify confirm current needs on the ground in the context of ongoing delivery and training
 - negotiate community plans and agreed actions
 - research present ideas for interactive biomedical animation and health literacy materials
 - identify and engage interpreters at the community level
 - conduct as required: health literacy workshops, focus groups, and/or education and training sessions to trial and develop interactive health animation and communications materials
- Work with key stakeholders at the *centralised governmental delivery level*
- Work with AIS on developing a health interpreting module
- Work with CDU and BIITE to integrate resources and practices into the delivery of their training
- Identify and collaborate with other relevant research and delivery programs
- Continue development of resource prototype/s, programs and processes
- Update and develop project website
- Present prototype/s to the Reference Group for approval
- Present at '*Chronic Diseases Network Annual Conference*', 9 – 10 September 2010
- Produce and submit a '*Project Progress Report*' for Reference Group and OATSIH, and a *brochure* to report-back to community participants

Phase 3: Implementing and Evaluating

(Ends around July 2011)

- Work with *Reference Group*
- Develop resources, processes and programs
- *EAL Visits*: conduct health literacy workshops, education and training programs, focus groups and/or trials in East Arnhem communities on use of interactive biomedical animation and health literacy materials
- Support the AIS to implement the health interpreter training module
- Work to increase routine use of health interpreters in all relevant settings.
- Work with CDU and BIITE to integrate resources and practices into training
- Work with various primary, secondary and tertiary health providers, and other relevant organisations to plan future development, strategy for role-out and to support usage
- Update and develop project website
- Identify and collaborate with other relevant research and delivery programs
- Conduct formative and summative evaluation
- Produce and submit final '*Project Report*', and a final '*Brochure*' to report-back to community participants

2.5 Evaluation framework and sustainability

The project will be embedded in an CQI-based evaluation framework incorporating 'front-end, formative and summative evaluation'.

Preliminary evaluation (before)

The preliminary evaluation took place during Phase 1 (*Scoping Study*) and enabled us to identify the project goals (2.1) It included a: literature review (qualitative), resource review (qualitative), survey (quantitative and qualitative) and stakeholder interviews (qualitative).

Formative evaluation (during)

This evaluation is iterative and provides on-going feedback to adjust and improve the project as it goes along. The project aims to collaborate with groups of people and practices to produce sustainable and evident improvements in health literacy. PDCA, PAR and process mapping will be explored as appropriate methodologies to continuously and collaboratively critically evaluate and improve the project, and identify areas of further theoretical and research work.

Summative evaluation (after)

The project will evaluate and report against the identified goals and be presented to OATSIH upon completion of the project.

2.6 Copyright

Intellectual Property will remain with the authors. Copyright for illustrations and multimedia will require negotiation, and will most likely be a license-to-use agreement.

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Appendix

People interviewed

Listed by organisation

Name	Position	Organisation	Community base	Interviewer	Other details
Colleen Rosas		AIS	Darwin	Michael, Trevor, John	
Josie Guy		AIS	Darwin	Michael, Trevor, John	
Chris Manners		AIS	Darwin	Michael, Trevor, John	
Karrina Demasi		BIITE	Bachelor	Michael	Department of Clinical Practice & Community Care, Faculty of Health, Business & Science,
Tracey Luke	Coordinator of the ACW course	CDU	Darwin	Michale	School of Community Services and Health
Chris Bell	Lecturer ACW course	CDU	Darwin	Michael	School of Community Services and Health
Christine Short	Manager	DHF	NT	Michael	Performance & Research Branch System Performance and Aboriginal Policy Division
Joe Wright		DHF			
Dr Christine Connors	Program Leader	DHF (Health Development)		Michael, Trevor, John	Preventable Chronic Disease Centre/Program
Dagmar Schmitt	Research and Evaluation Officer	DHF (Health Development)	Darwin	Michael and Trevor	Health Promotion Strategy Unit
Bernie Shields		DHF (Health Development)	Darwin	Michael and Trevor	
Kacy Kohn	Area Service Manager	DHF (Remote Health)	Yirrkala		
Heather Keighley	Public Health Coordinator (Groote)	DHF (Remote Health)	Anurugu	Michael	Alyangula, Anurugu, Umbakuma, Bickerton Island, and Numbulwar
Kay Coppa	Public Health Coordinator (Central Arnhem)	DHF (Remote Health)	Milingimbi	Juli	Yirrkala, Milingimbi, Ramingining and Gapuwiyak
Rhonda Powell	Area Service Coordinator	DHF (Remote Health)	East Arnhem South	Trevor	
William Costigan	Area Service Manager	DHF (Remote Health)	Gapuwiyak, Ramingining	Trevor	
Stephen Bryce	GP	DHF (Remote Health)	Gapuwiyak	Trevor	
Jeff Cook	Health Service Manager	Laynhapuy Health Service	Yirrkala	Michael, Juli	Laynhapuy Homeland Centres
Jeff Bowman	Health Manager	Marthakal Health Service	Galiwin'ku	Michael	Homeland Centres
Liz McDonald		Menzies School of Health	Darwin	Michael	
Dr Paul Burgess	Public Health Medical Officer	Menzies School of Health Research	Maningrida/Darwin	Michael, Trevor, John	
Harvey Creswell	Policy and Planning Officer	Miwatj	Nhulunbuy (office)	Michael, Trevor, Juli	Gunyangara, Galupa, Wallaby Beach, Ngalkanby Health Service
Michelle Dowden	Manager	Nalkanbuy Health Services	Galiwin'ku	Michael, John, Trevor	

Survey Respondents

Listed by community (note: empty cells are where information was not provided).

Name	Position	Organisation	Community base
Jenni langrell			Angurugu
Heather Keighley	Public Health Coordinator (Groote and Numbulwar)	DHF	Angurugu
Crystal Griffiths			Angurugu
Robert Manning			Angurugu
Jean Rurrukanbuy,	AHW	Galiwin'ku Clinic	Galiwin'ku (interviewed by Wangurru)
Thomas Yalanhdhu	ACW		Galiwin'ku (interviewed by Wangurru)
Guyupul	ACW		Galiwin'ku
Teresa Ngurruwuthun	RAHW	Gapuwiyak Clinic	Gapuwiyak (interviewed by Wangurru)
Lisa Ngurruwutun	SAHW	Gapuwiyak Clinic	Gapuwiyak (interviewed by Wangurru)
Trudy Garramara	ACW		Gapuwiyak
Amanda Ngurruwutthun	Admin worker		Gapuwiyak (interviewed by Wangurru)
Stephen Bryce	GP	DHF (Remote Health)	Gapuwiyak
Vicki Myers			Gapuwiyak
Harvey Creswell		Miwatj Health	Gunyangara, Galupa, Wallaby Beach, Ngalkanby Health Service (Nhulunbuy – office)
Nick Power			Laynhapuy Homelands
Jeff Cook	Health Service Manager	Laynhapuy Health Service	Laynhapuy Homelands (Yirrkala)
Kay Coppa (1)	Public Health Coordinator (Central Arnhem)	DHF (Remote Health)	Milingimbi
Kay Coppa (2)	Public Health Coordinator (Central Arnhem)	DHF (Remote Health)	Milingimbi
Roselind Djuwandaynu		DHF (Remote Health)	Milingimbi (interviewed by Wangurru)
Bruce Coppa	Doctor	Milingimbi	Milingimbi
Helen Gowanbuy	Cleaner	Milingimbi Clinic	Milingimbi (interviewed by Wangurru)
Julie Galalathana		Strong women strong babies, strong culture	Milingimbi (interviewed by Wangurru)
Sandra Mulanyawuy	Admin		Milingimbi (interviewed by Wangurru)
Nuwanjali Marawili			Milingimbi
Wesley Dhamarrandji			Milingimbi
Elizabeth Ganygulpa			Milingimbi (interviewed by Wangurru)
Helen Gowenbuy Dhamarrandji			Milingimbi (interviewed by Wangurru)
Elizabeth Wurrulunga			Milingimbi
Judy Lirririnyin	Milingimbi Clinic		Milingimbi (interviewed by Wangurru)
Rhonda Gungarinya			Milingimbi
Judith Lirririnyin			Milingimbi (interviewed by Wangurru)
Barbara Dhamany			Milingimbi (interviewed by Wangurru)
Angela Woltmann	Medical Director	Miwatj Health	Nhulunbuy
D Frumenzi		Miwatj Health	Nhulunbuy
Terry Yumbulul			Nhulunbuy
Biyay'nyu Gaykamaru			Ramingining
Sue Colquhoun	Yirrkala Clinic	DHF	Yirrkala
Di Ofa	Yirrkala Clinic	DHF	Yirrkala
Cassie Daniels	Yirrkala Clinic	DHF	Yirrkala
Jeff Baxter	Yirrkala Clinic	DHF	Yirrkala
Karen Coyle		Remote Outreach Midwife Health Development	Yirrkala

APPENDIX

Name	Position	Organisation	Community base
Catherine Moody	Project Officer, Child and Youth Health	DHF (SWSBSC and Community Child Health Workers)	
Chris Bell	Lecturer ACW course	CDU	
Jeanette Pastor		Other	
Marie Wangurru		Other	
Norma Ellis		Other	
Yolngu Consultants		Other	
Nick		Other	
Coralie Achterberg		CDU	
Unidentified 1			
Unidentified 2			
Unidentified 3			

Resources Review

Resource	Organisation & UR	Description	Representation of body/illness (aesthetic)	Functionality	Usability (intuitive etc)	Communication (voice-over, dialogue)	Other comments
Visible Body	Argosy Medical.com http://www.visiblebody.com	Web-based virtual 3D interactive body. Subscription-based resource for Marketing and Educational content about the body communication Patients, Students and Customers. US \$36 per year for educational use 1700 3D models of Body. Can develop customized solutions	3D models, traditional scientific style rendering (veins are blue, artery red etc). Cutaways of body revealing ever diminishing parts	Mouse driven, requires Internet connection. Also available on iPhone as zoomable body	Quite good, requires practice.	No	Have made enquiries to develop a customized solution for iPad
Your Practice Online	www.yourpracticeonline.com.au/	Web based company aiming to build and sell internet resources for all aspects of health including multimedia. They have many multimedia presentations; 2D, 3D, text and voiceover. These are for sale and use on websites. Although there are some examples of healthy body systems the focus is more on morbidity and procedures.	Classic medical type illustration	Plenty of interactivity, buttons for specific info, 3D rotate and zoom	Average	Can choose	
Health Posters	Various	A number of Posters were reviewed. These posters were made for use in a Hospital/Clinical setting	Classic medical illustration aesthetic, Cutaways, colours, transparencies interspersed with text blocks	Stand alone, Doctor Patient/student	Written English language, familiarity with biomedical knowledge and concepts	English	
DVD and flip books	DHF	Illustrations, songs and messages related to diabetes and dialysis and self management	Illustrations based on photographs. Jimmy Little on DVD		Under evaluation	Strong story and sequence based	Didactic
Sharing The True Stories Resources	www.cdu.edu.au/stts	Flip books explaining body functions (focus on renal) Videos talking about communication processes Reports about the research	Stylised images based on photographs	Straightforward, not exactly sure what you will get, too many talking heads	OK	Bilingual with translations and subtitles	
DHF Storyboards	Bernie Shields DHF Remote Programs	Innovative, hand-on resource Felt boards (land) with felt circles and small icons or symbols (adults, children, behaviours/habits, and diseases.) Participants map/represent own/family/community health stories/possible futures Usually presented in workshop and used in conjunction with more traditional health charts	Specifically designed for Aboriginal people Mostly abstract representative symbols Simple/user-friendly Tactile	Manipulated physically Relies strongly on presenter Very low tech Can be modified and embellished by users	Client-centred User-friendly No skills required Has been good feedback	Integrates discussion of medical, social, and political aspects of public health Ownership of process by participants who end with own kit)	Values all participants and their knowledge as equally important
Games	Various	Various games, simulation activities, i.e. snakes and ladders (crocs and trees) to explore healthy eating choices. Most games I saw were focused on lifestyle messages.	Nice productions	Didn't try			Have heard people find the games demeaning