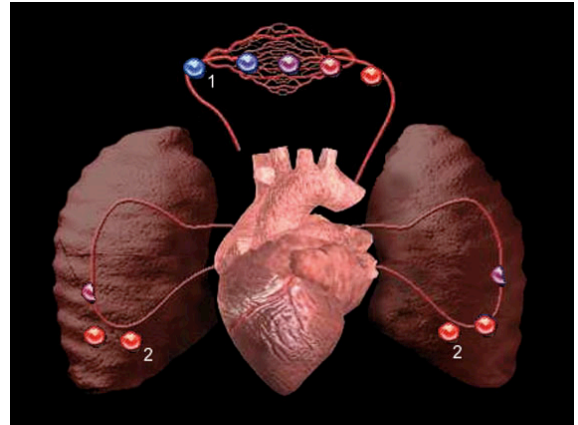


**Final Report for the National Rural Primary Health Projects Initiative**

**Healthy Breathing and Heart: Stage 2**

**January – December 2009**



Dr Mark Howard  
Institute for Breathing and Sleep  
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## Executive summary

Miscommunication between English speaking health professionals and non-English speaking Aboriginal patients is a serious and well-documented problem in Northern Australia. A team of bilingual bicultural Yolŋu (northeast Arnhemland Aboriginal) interpreters came together with Charles Darwin University researchers to plan and develop a digital multimedia resource for use in Aboriginal patient education and medical interpreting around hearts and lungs. This project was Stage 2 of a project originally funded by the Institute for Breathing and Sleep in which a larger group of Yolŋu interpreters came together to assess the possible use of multimedia to improve communication between Indigenous patients and health care providers who do not share the same cultural and language background. Stage 1 made recommendations which were taken up and implemented by Stage 2 which is the subject of this report.

Stage 2 began with the identification of a group of bilingual bicultural interpreters who have had experience in health interpreting. This group met together with CDU academic staff who were involved with Stage 1 and have worked on communication issues in cross-cultural medical contexts for many years. The collaborative analysis began with discussion in Yolŋu languages about key Yolŋu and biomedical concepts for building shared understandings around healthy hearts and lungs. This led to extensive work in evaluation of existing multimedia resources, and the selection of the most useful available resources. Permission for the use of the copyright images and animations was obtained. The resources were integrated into a narrative sequence and a narrative text. The text was produced collaboratively and elaborated the functions of heart and lungs – from a Yolŋu point of view, but working with the biomedical model of the body. A first version of the narrative was recorded, and back translated into English for checking by a medical professional. A multimedia designer integrated the various images and animation into Version 1. A period of intense evaluation followed, with suggestions being incorporated into Version 2. Once the sequence was agreed, a final recording of the audio was prepared in a studio and integrated into the multimedia process. The DVD was finalised, a cover and notes prepared, and 50 copies of the DVD were prepared and sent out to remote clinics, the Aboriginal Interpreter Service, The Batchelor Institute of Indigenous Tertiary Education (where training for interpreters and health workers take place) and a website was set up to publicise the project, and for ongoing evaluation and further dissemination of the DVD. The website can be viewed at [www.cdu.edu.au/centres/yaci/im/index.html](http://www.cdu.edu.au/centres/yaci/im/index.html). An IBAS Education Grant has been received by the researchers to extend the resources to include an explanation of asthma and COPD in 2010. The researchers are continuing to seek funding for further development of this resource to extend to other parts of the body, and other languages.

## Introduction

Large proportions of both the huge burden of disease in Indigenous Australians and the substantial gap in health outcomes between Indigenous and non-Indigenous Australians relate to chronic diseases which affect the health of respiration and circulation. Chronic obstructive lung disease, asthma, respiratory infections, heart disease and sleep-disordered breathing together account for the largest source of mortality and chronic disability in both Indigenous and non-Indigenous communities. In addition to redressing socio-economic inequities and health service delivery, there is a major need to further develop health literacy in Indigenous communities and to do so in culturally appropriate ways. There are very few health education resources relating to respiration and circulation which have been designed specifically for Indigenous Australians and which are suitable for deployment in remote communities and rural health settings. Respiration and circulation are integrated body systems, and the uptake, transport and utilization of oxygen by the body, and how wakefulness, exercise and sleep influence these processes, are best treated as a single complex story for which many metaphors are to be found within Indigenous culture.

The Cooperative Research Centre for Aboriginal Health project “Sharing the True Stories” identified the need to develop contexts and resources for the building of ‘shared understandings’ outside and prior to the cross-cultural clinical encounter in Aboriginal health (Cass et al, 2002). Key aspects of these shared understandings in the western health model (diagnosis, prognosis, treatment, prevention) need to include the biomedical model of the body – anatomy, physiology, respiration, circulation, metabolism etc.

In this context, collaboratively researched and developed learning materials have significant potential for use in the work of health professionals in cross-cultural contexts, in remote and rural settings and generally in Indigenous health promotion. Firstly, they will build in the Indigenous community the conceptual basis which will contribute to healthy behaviours, and shared understandings of disease mechanisms, treatment strategies and health outcomes. This will serve to demystify western biomedical perspectives and practices and create opportunities to align traditional and mainstream health practices. The learning materials will be particularly useful for doctors, health care workers and interpreters working with Aboriginal people who speak little English and have a traditional world view.

The Healthy Breathing and Heart Project originated with a workshop in late 2007 at Charles Darwin University. Prof Rob Pierce from the Institute for Breathing and Sleep met with a group of Yolŋu (northeast Arnhemland Aboriginal) interpreters to critically evaluate the current and potential uses of biomedical multimedia in patient education and interpreting in clinical contexts. The meeting focussed upon multimedia representations of the respiratory and pulmonary systems which had been sourced through collaborations with the Biomedical Multimedia Unit at the University of Melbourne. It was facilitated by two researchers from Charles Darwin University, Prof Michael Christie and John Grotorex, both fluent speakers of Yolŋu languages, and two postgraduate students. A detailed account of the Stage 1 workshop can be found at [www.cdu.edu.au/centres/yaci/im/index.html](http://www.cdu.edu.au/centres/yaci/im/index.html)

Stage 1 ended with a decision to continue to work in collaboration with Prof Pierce, IBAS, and the Indigenous consultants to evaluate, select, configure and further develop a suite of multimedia resources for use in patient education and medical interpreting related to ‘Healthy Breathing and Heart’. Funding was received from the National Rural Primary Health Project Initiative, Dept. Health and Ageing for Stage 2.

The purpose of this report is to provide a detailed account of Stage 2 and to provide links to further web-based information images and resources for:

- the funding body: the National Rural Primary Health Initiative
- support bodies: the Institute for Breathing and Sleep, Charles Darwin University and the Biomedical Multimedia Unit at the University of Melbourne
- other participating organisations including the Aboriginal Interpreter Service.

Alan Cass, Anne Lowell, Michael Christie, Paul Snelling, Melinda Flack, Betty Marrnganyin and Isaac Brown, (2002) 'Sharing the True Stories: Improving communication between Aboriginal patients and Health Care workers', *Medical Journal of Australia*, 176, 20, 466-70

## **Project aims**

The original aim was stated as:

To work in collaboration with Indigenous consultants to evaluate, select, configure and further develop a suite of multimedia resources for use in patient education and medical interpreting related to Healthy Breathing and Hearts.

## **Activities undertaken**

### **Project Plan Summary**

*December 2008:*

Finalisation of plans and seeking interest from people to be involved in the Healthy Breathing and Heart Project, Stage 2. Obtaining copyright permissions for workshop images and multimedia, and clearance for multimedia with potential use.

*February 2009:*

- research team finalised
- collection of hard and multimedia copies of existing resources for evaluation (based on Prof Rob Piece's work and other sources) finalised.

*March – May 2009*

Work with Yolŋu team members and other Yolŋu advisors as appropriate to:

- confirm depth and range of concepts to be communicated (from a Yolŋu perspective) based on the findings of Stage 1.
- identify strategies for effectively communicating these concepts with particular attention paid to the contexts of building shared understanding and the roles of the various people often involved in the process.
- critically evaluate all available resources to identify useful existing media
- identify range and key features for any new media that need to be developed
- develop ethics submission for development and evaluation phase of the project

*May 2009*

Workshop with Project team and advisors to:

- provide feedback to the Advisory group from Yolŋu consultants about currently available media and specific needs for further development
- further evaluate potentially useful resources with full team
- identify the particular contexts in which the resources may be used and implications for next stage of the project
- confirm the scope of the current project, achievable with current funding (based on extent of existing suitable media and costs of developing new media) identify strategies/process for facilitating optimal use of resources

#### *June 2009 – August 2009*

- Permission for the use of the copyright images and animations obtained.
- Collaborative work with the Darwin research team to
- configure available representations,
- define and develop further required resources.
- trials of resources one month.
- implement evaluation process.
- feedback to multimedia developers and modification of resources as required.

#### *August – October 2009*

- finalisation of the most useful available resources.
- resources integrated into a narrative sequence
- narrative text developed collaboratively elaborating the functions of heart and lungs – from a Yolŋu point of view, but working with the biomedical model of the body.
- first version of the narrative recorded
- back translation into English developed
- checking by a medical professional from the CDU Graduate School of Health
- ongoing evaluation and implementation of feedback
- revision of text and configuration of animations

#### *November 2009*

- multimedia designer integrates selected images and animations into Version 1.
- second audio voiceover recorded and integrated into the software.
- evaluation of the resource by Indigenous health workers, students, and others.
- Version 2 developed from suggestions for improvement
- final studio recording of the audio
- audio recording integrated into the multimedia process
- DVD finalised
- cover and notes prepared
- 50 copies of the DVD sent out to remote clinics, the Aboriginal Interpreter Service, The Batchelor Institute of Indigenous Tertiary Education (where training for interpreters and health workers take place)

#### *December 2009*

- website set up for access to web version of final product, ongoing evaluation and further dissemination of the DVD.
- plans to have the resource evaluated by speakers of non Yolŋu languages through the Aboriginal Interpreter Service
- preparation of draft final report

## **Community and other Consultation**

The strength of this project was that the development of the resource was negotiated with members of the Yolŋu community at each stage

- deciding upon the research team,
- consulting over appropriate ways to tell the biomedical story using Yolŋu languages
- negotiations over the selection and configuration of digital resources
- evaluation within the wider community.

The project also depended upon ongoing consultation with nonIndigenous health professionals in the community.

## **Delays and Barriers Identified**

There was a significant delay in the early stages of the project when the Yolŋu interpreters identified a need to deal in detail with the nature and function of blood before the proper functions of hearts and lungs could be understood. Further work with the Yolŋu consultants was required to identify the multimedia representing how blood is made, and the components and the function of blood. Graphics and new story line were integrated into the resource.

There are few Yolŋu interpreters available in Darwin for work on research projects so we had to be flexible to accommodate the many demands on the time of the Yolŋu members of the team.

Obtaining permission to use resources that were identified by the Yolŋu participants as the most useful also delayed progress as some organisations either refused permission or were slow in responding to requests for permission. Refusals required further work to identify alternative resources.

It was originally proposed that a learning module in cross-cultural health communication for medical and allied health students be finalised as part of Healthy Breathing and Heart. This sub-project has begun and is continuing in the form of a Short Course on Health Communication, which is also being funded by the National Rural Primary Health Projects Initiative in a project called 'Taking control of chronic disease: strengthening communication and education strategies supporting self-management for Indigenous consumers'.

It was also originally proposed that an academic paper would be produced from the project. A postgraduate student working on the project, Christian Clark submitted a paper called 'Digital Objects Working Epistemic and Other Boundaries' which was submitted to a journal called Spontaneous Generations, but has not yet been accepted for publication. This paper looks at some of the knowledge and representation issues which arose from the workshops with Prof Pierce.

Anne Lowell and Michael Christie are also working on a paper which will begin with the insights gleaned from the Healthy Breathing and Heart program, integrated with the research in clinical settings which will come out of the Taking Control project (above). This paper will be prepared by May 2010 and submitted to Social Science and Medicine.

## **Evaluation Framework**

The evaluation strategies included:

- finding speakers of Yolŋu languages willing to spend a few hours looking at the resource and giving their comments about it

- talking to them about their understandings of the nature and functions of blood, heart and lungs
- helping them to open and control the resource and getting feedback on the functionality of the resource and the way it can be used
- asking about the representations and recording the comments made.
- asking about the soundfile, how it contributed to the overall product, and any changes which could be made
- asking about what they had learnt from using the resource, and recommendations for improvement
- discussion about the contexts in which the resource could be used and plans for distribution

## Outcomes

The scoping phase of Stage 2 began in March 2009. Jane Galathi, Rachel Baker and Helen Guyulun who were all experienced interpreters worked with project facilitator Anne Lowell over a period of three months (see the photograph on the cover of this report).

In the scoping phase, the team worked together to

- build on the findings of Stage 1, confirm the range and depth of fundamental biomedical concepts to be communicated in building shared understandings around hearts and lungs
- identify strategies for effectively communicating these concepts with particular attention to the contexts of building shared understanding and the roles of the various people often involved in the process in different contexts
- critically evaluate all available resources to identify useful existing media
- identify the range and key features for any new media that needs to be developed

Following a lengthy process of evaluating existing educational resources related to the respiratory and circulatory systems the Yolŋu team members identified a number of key features for an educational resources designed specifically for use with Yolŋu consumers. They concluded that:

- a DVD based resource segmented into chapters is the most effective format for the resource
- Information needs to be fully contextualised e.g. heart and lungs shown within the body then zooming in from the whole body onto specific area
- sufficiently detailed biomedical explanation translated into spoken Yolŋu Matha (language) is essential.
- related concepts which are crucial to understanding respiration and circulation also need to be fully explained e.g. the structure and function of blood
- realistic animations (not too stylised) which clearly illustrate function are necessary to support the narrative explanation

As decided by the Yolŋu consultants in Stage 1, the initial and primary focus was on the normal structure and function of the circulatory and respiratory systems rather than disease processes or treatment. The concepts included within this were:

- an explanation of oxygen and carbon dioxide
- respiration (movement of air in and out of the lungs)
- exchange of gas between the lungs and circulatory system
- the circulatory system as a mechanism to move gases around the body
- the heart as the pump for the circulatory system.

The interpreters soon identified the need for work on deeper understandings relating to blood as essential for any subsequent description of the systems to make sense. The interpreters worked to further develop their understandings of the biomedical model of circulation and gas exchange, ways of telling the story of blood in their own languages, and the potential role of multimedia in building shared understandings.

The original suite of multimedia from the Biomedical Multimedia Unit at the University of Melbourne was supplemented by further extensive internet and library searches for multimedia dealing with blood. It was a difficult challenge to find existing resources that met the key requirements identified by the interpreters, particularly for the circulatory system. A further problem was that while some excellent multimedia objects were located it was not always possible to get permission to use the copyrighted material.

In the Development Phase, the consultants worked together to produce a storyboard which linked the various multimedia sequences to the narrative of circulation, gas exchange etc that they had developed in Yolŋu languages. This work involved finding ways of using the highly organic metaphors of body and life processes at work in Yolŋu languages to describe and interpret the biomedical models of human physiology based often on a machine metaphor. The careful and collaborative development of a sufficiently detailed and meaningful oral explanation, and selection of appropriate animations was a time-consuming and challenging process as so much of the Western cultural knowledge related to function of systems within the body is not shared by Yolŋu.

Throughout this phase the developing narrative and associated visual resources were continually evaluated with the Yolŋu team members and other interested Yolŋu. The first draft was then further evaluated with Yolŋu community members, including health workers. Feedback from this process then informed the next level of the development of the resource.

The interpreters practised telling the story while they watched the animations. Explanations for each section were developed, draft recordings were made, and Michael Christie provided a back translation to English which was checked for accuracy from a Western medical perspective.

Once the suite of resources, the storyboard and the narrative were finalised, Trevor van Weeren from Merri Creek Productions worked with Galathi to integrate the sequences into a single digital resource and prepare a voice-over.

Recommendations for the final product were for

- the development of a zoomable animation of a complete transparent body showing lungs, heart, circulation, gas exchange and digestion – as a device to continuously relocate the animations of heart and lung in the wider context of the body.
- transcription and studio recording of a final voiceover track in Djambarrpuyŋu (the most widely spoken Yolŋu language, universally understood by Yolŋu)

A key outcome of the project, apart from the DVD, was the website which can itself be used as a resource for training health workers, patient educators and interpreters, and the training of nonIndigenous health professionals. A web version of the final resource can be found at: [www.cdu.edu.au/centres/yaci/im/resources2.html](http://www.cdu.edu.au/centres/yaci/im/resources2.html)

## **What is sustainable?**

The Healthy Breathing and Heart DVD has already begun to take its place in the toolbox of resources for patient education and interpreting in Yolŋu contexts. The images and

animations have been cleared of copyright issues and are now freely available for further work. The collaborative research arrangement between IBAS, CDU and the Yolŋu people of Arnhemland has been strengthened.

## **Project challenges**

The aim to test the use of the digital resources in clinical contexts was not fully realised. Prof Pierce had intended to be working as Thoracic Specialist at Royal Darwin Hospital during the dry season of 2009 – where he would have supervised that part of the project, but he died tragically in January 2009. There is more work to be done fine-tuning the resource, developing further versions on the basis of ongoing feedback, and integrating its use into medical contexts.

## **Lessons learnt**

It is clear that the usual conventions for representing movement, depth, scale, three-dimensionality in western graphic work do not immediately translate as meaningful to Aboriginal viewers. Looking back it is hard to decide whether the huge complexity of configuring a range of digital resources – each with their own set of conventions for representation – was justified. For the same amount of funding it may have been possible to start developing new animations collaboratively with Aboriginal artists and interpreters ‘from scratch’. Animations are extremely expensive to make, so we very probably went about it in the best way, but we continue to investigate both avenues.

## **Conclusions**

The project has produced a digital resource which will be of considerable use inside and outside of clinical contexts. Based on the notion that communication is the building of shared understandings, the Healthy Breathing and Heart DVD promotes discussion of the structures and functions of healthy hearts and lungs both within the Aboriginal social and educational contexts, and between Aboriginal patients (and their families) and English-speaking professionals.

The collaborative methodology for integrating the perspectives and practices of remote indigenous knowledge authorities, health workers and interpreters, experts in biomedicine, and academic specialists in cross-cultural research and communication has again proved successful and sustainable. This project was one of a range of similar cross-cultural research collaborations conducted by the Yolŋu Aboriginal Consultancy Initiative at Charles Darwin University. Other examples can be seen at [HUwww.cdu.edu.au/yaciUH](http://HUwww.cdu.edu.au/yaciUH).

## **Recommendations**

### **Next steps:**

- distribution of a further 40 copies to Yolŋu clinics, schools, renal unit, Royal Darwin Hospital, Aboriginal Interpreter Service, Batchelor Institute of Indigenous Tertiary Education (interpreter and health worker training courses)
- online proforma for feedback and access to more copies of the resource.
- full report of Stage 2 on the Yolŋu Consultants’ Healthy Breathing and Heart website [HUwww.cdu.edu.au/centres/yaci/im/index.htmlUH](http://HUwww.cdu.edu.au/centres/yaci/im/index.htmlUH)
- web-based version of the resource available through the Healthy Breathing and Heart website.

- Funding has been obtained through an IBAS Education Grant for further extension of the resources to include sections on asthma and COPD.

### **How outcomes could be used elsewhere.**

- We are working with the Aboriginal Interpreter Service to develop a plan for customising the resource to other key NT languages.
- We will use the collaborative methodology to investigate the development of similar resources for other parts of the body and their healthy functions
- We will make the practices and the advantages of the transdisciplinary research model widely available through the website.

## **Acknowledgements**

We acknowledge Prof Rob Pierce who through his dedication, concern and good will inspired this project and made it happen.

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