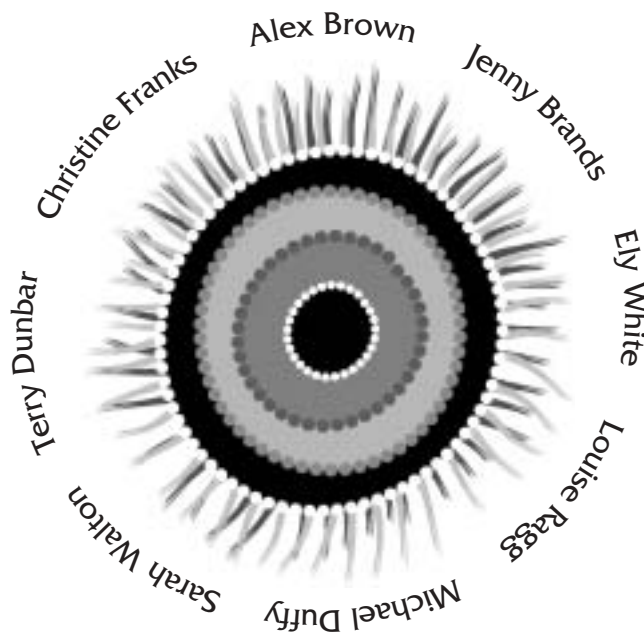




Research partnerships: Yarning about research with Indigenous peoples



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Workshop Report 1

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Designed by Sarah Walton, CRCATH
Painting by Susan Abbott Napanangka

The Cooperative Research Centre for Aboriginal and Tropical Health wishes to thank Susan Abbott Napanangka for the use of her painting for this report.

The painting reflects the country after the rains, with everything fresh and newly washed. All the colours are glowing to represent the vitality and vibrancy of the country as it renews itself after the long dry season. The red ochre represents the different Aboriginal communities and their essential relationship with the land, while the circle of gold paint is symbolic of the wholeness of community life and the absolute importance of functional, intercultural partnerships. The circle is surrounding and protecting the different professions as they work together...

People are working in equivalence and can be seen travelling to each of the communities to teach, to carry out different health programs, and to town to learn new skills. By working this way, the older members of the community can begin to trust new methods of doing things that will enhance their contemporary Aboriginal life. It is in these small groups that serious issues can be discussed in privacy.

Also, working equivalently brings about deeper friendships, enabling people to fully enjoy and value a different culture, both ways.



Foreword

Human beings are creatures that innately seek out and nurture relationships. In most cases this will transfer over into the workplace and across many social activities. However, sometimes this instinctive relationship-forming process is replaced with a trained and coded behaviour, particularly when the interactions are intercultural and concern professions and professional status. This in fact characterises the experience many Indigenous Australian people have of health and medical research in their communities. As a result, they have developed an attitude of 'We don't like research'.

For a decade or more, health and medical research literature has signalled some of the underlying issues concerning research processes, research ethics, funding and lack of control by Indigenous communities and Indigenous participants. Some of the issues were recently publicly summarised by Kim Humphery (VicHealth Koori Health Research and Community Development Unit Discussion Paper No 2: p.10) when he stated that:

....Indigenous writers have sought to move debate beyond the notion of 'research guidelines' by seeking to treat Western research traditions, broadly defined, as a 'tool box', from which they can take whatever methods are deemed appropriate to Aboriginal knowledge production, and insisting on the development of new paradigms of research governed by Aboriginal 'Terms of Reference'. As Winch and Hayward (1999: 26) argue 'Aboriginal Terms of Reference does not simply mean writing a set of guidelines for "doing business with Indigenous people". Rather it means the consideration of an Indigenous world view'. Here, there is both an acceptance of the 'usefulness' of research as an activity but also an insistence on the need for non-indigenous researchers and research organisations to accept and work with emerging Aboriginal standards of inquiry and criteria of validity.

The CRCATH places a great deal of importance on the need for scientists to reassess traditional health and medical research practices and to challenge what is meant by 'quality research', 'valid research outcomes', and 'value-free research'. It is a significant part of our agenda for change.

To move this change agenda towards the achievement of an increase in research practices that are more health outcomes oriented, and in the process to strongly encourage research processes that allow for real contribution and control by Indigenous Australians, the CRCATH has funded a three year research project to proactively research and test management models and systems. This research project is more commonly referred to as the CRCATH 'Links' Project. The Yarning Workshop series data will be collated, and importantly, will inform the Links Project.


I urge you to read the Yarning Workshop 1 Report with the understanding that it describes a workshop that was developed and conducted by Indigenous people who are experienced in health and education research. The processes during the development phase, throughout the workshop and the following evaluation interviews were instrumental in demonstrating what 'nurturing of relationships' means. I am confident that you will find the Report thought provoking. In particular, I hope that it challenges health and medical researchers to be more reflexive about their way of operating, whether it is in the delivery of services, or when conducting research.

In closing, I would like to pay tribute to Ms Christine Franks for her insights and eldership throughout this experience. Ms Franks is an Indigenous MAE (from ANU) holder who works as an Indigenous Health Educator with the Alice Springs Health and Community Services Unit, Department of Health and Community Services. Many thanks to Ms Franks' work colleagues who graciously made it possible for her to play a lead role with the Yarning Workshop and with the finalisation of the Yarning Report.

Enjoy the Yarn.

Terry Dunbar





I was working in the Pitjantjatjara lands in the mid 1980s. A senior man of the host community who was a colleague became quite distressed after lengthy discussions with researchers from Adelaide who wanted to do further research about health and social issues in the community. He said he'd tried to talk with the researchers about how he and others in the community saw the issues, but 'Kulini wiya, they wouldn't listen'. They kept interrupting and defining the issues the way they saw them.

He went away and reflected long and hard on what had happened, and talked to family and significant Aboriginal people in his and other communities. Then he asked another colleague and I to work with him. He was the lead investigator of the research, and we were co-researchers. Later many other people became involved in the process.

We travelled to many communities, where we would have long discussions about health and social issues of concern to members of the communities. The discussions were rigorous explorations, drawing on community members' knowledge of traditional structures and family values, and the understandings of contemporary Western culture brought by my colleague and I. Our discussions made explicit both cultures and ways of life, and helped all of us understand more deeply.

It is evident Aboriginal people have always done research...about the environment, where to go and when. They knew how to measure very precisely the numbers of people needed in groups for social, emotional, spiritual and physical wellbeing. It was very critical that research was conducted, and that it had to be a continuous process, because it was a matter of survival on a daily basis. So these discussions about health and social issues were conducted with the utmost integrity and intellectual rigour.

Christine Franks





Introduction

Research partnerships: Yarning about research with Indigenous peoples was a workshop held in Darwin on April 10-11, 2001. The workshop was sponsored by the Cooperative Research Centre for Aboriginal and Tropical Health (CRCATH). It was one point in a process which had begun months, even years, earlier, and which is on going. This report describes the process to date.

In keeping with the workshop title of 'Yarning', and the emphasis placed on communication throughout the process, this report makes explicit the web of relationships, interactions and ways of working that make up the process in action.

The report endeavours to make clear the links and connections between people which have brought us to this point, and the interactions through which ideas emerge, evolve and are tested.

Christine Franks and Sally Matthews met in the early 90s at a cross-cultural workshop in Alice Springs. Christine Franks was a member of the group running the workshop and Sally Matthews one of the participants. There was much discussion about working in equivalent intercultural partnerships, and over the years Christine and Sally continued those discussions, along with conversations with many other people.

During 2000, those discussions began to focus on the issue of the dissemination of research findings from the CRC. Sally Matthews felt the CRC was doing valuable research, but that the impact of this work could be enhanced through more appropriate forms of dissemination in Indigenous communities. Sally contacted Christine to see if she would consider working with the CRCATH's Communications Officer Louise Ragg to design and organise a workshop about the dissemination of research findings.

It seemed to me that if we were going to truly address this issue, we had to start at the beginning. Dissemination is just a part of the process. If we look at dissemination in isolation, we are still missing the true communication that's needed for a research partnership.

Christine Franks

Around all this and right through it is communication. How do we communicate and involve people in this? How do we make sure that the research expertise and the 'understandings' people come together?

And often researchers don't know how to do this. Often researchers have focussed on what the issue or the problem is, not how to communicate it?

Sally Matthews

So the conversations broadened. Christine sought the CRC's approval to engage Ely White, a linguist, in the process, to help focus on the critical issues of communication and the use of language. Christine and Ely had worked together over many years in the Pitjantjatjara lands, where they were taught by anangu and yapa elders about how to work collaboratively in Aboriginal countries.

The work we were involved with was research, and the elders were always the ones driving the research. They showed us how to listen and to learn about the process. They taught us about the relationships within the kinship structure, how we could draw on that structure and adapt it to contemporary issues. One of the things we truly learnt through this way of working, was that it was people first and information second. And in this way, you can get results that work.

Christine Franks

So in the same way, Christine, Ely and Louise started working together. They began a process of talking, talking with everyone who'd been invited to the workshop. Each interaction, each new relationship, broadened and deepened the communication. Each person became an integral part of the process, their contribution heard and valued. And each brought their own circles of other relationships, others to contribute their ideas and energy and experiences.



Ely brought to the process an ability to analyse language, and to see how what we say or write reflects what is really going on in relationships, particularly relationships of power imbalance. The learning she and Christine had done about processes of communication evolved, through discussions with Terry Dunbar, into a plan to begin the workshop by setting Rules of Engagement, protocols for communication throughout the workshop.

Louise Ragg brought a practical dimension to the process, with her understanding of the CRC, of communications, and her endless supply of energy, enthusiasm and ideas.

One of the key ideas that set the tone of the workshop was to split participants into Indigenous and non-Indigenous groups. This idea arose out of discussions with Terry Dunbar, Mai Katona and Joan Cunningham. Gradually, the discussions were gathering momentum and excitement as more and more people became involved.

Alex Brown contributed the concept of a Geoffrey Robertson-style *Hypothetical* to set the context of research in Indigenous communities, and introduce the essential Indigenous humour to the workshop. The ideas were triggered through talks with Christine Franks and Ely White when the characters and themes of the *Hypothetical* began to take shape. These were further developed, scripted and presented by Alex Brown.

People responded really well to this way of working. Both Indigenous and non-Indigenous researchers agreed to work in partnerships, and this process was a great example of a research partnership. We had so many people with vision and commitment coming together, and each one brought ideas and energy.

Christine Franks

The invitations that were sent out inviting participants to the workshop asked them to bring an example of a research project they considered to have been effective within their own cultural group.

That is, Indigenous researchers were to bring examples of research done in Indigenous communities, and non-Indigenous researchers to look at research in non-Indigenous communities. Participants were also asked to consider and respond to the following questions prior to the workshop.

- A. What, in your experience, are the most important factors to consider in seeking improved Indigenous health outcomes through research?
- B. How would you describe the 'ideal' (best practice) approach to communicating with Indigenous communities about research? To what extent have you observed this 'ideal' being practiced in Indigenous research projects that you have undertaken/ been involved with/observed? Please provide an example.
- C. What do you think are the major impediments to successful communication about research?
- D. What do you think are the keys to successful communication about research?

Five responses were received to these questions prior to the workshop. (These responses are contained in Appendix A.) The responses indicated thoughtful and perceptive reflection, and clearly identified key factors in the conduct of effective research about Indigenous health. **A major theme was the importance of relevant and purposeful research and a commitment to action or change as an outcome of research.** The importance of considered approaches to the development of research projects was also highlighted. One respondent linked this to the key academic concept of 'getting the question right':

If we are asking the wrong question we are heading down the road of low impact research ... To ask the right question, it is important to ask the people first. If health problems are identified locally, there is more chance that research will be responsive to need. The findings are then more likely to have impact ...

It is better science to get a view from the inside. Findings are more valid and are therefore likely to produce more realistic outcomes for communities ... Expert driven agendas ask the wrong questions and come up with less useful answers ... This kind of science needs to be questioned more rigorously.

John Grundy

Communication processes were another key factor. Time and care in communicating thoroughly were seen as vital, and lack of attention to communication identified as a major barrier to successful research.

There must be considerable time set aside to bridging cultural gaps and establishing clear and informed understanding for researchers on the view and ideas of the Indigenous people involved and vice versa. This includes the recognition, valuing and utilisation of Indigenous knowledge and communication skills.

Yin Paradies

(A major impediment) is language – if the researchers don't speak the first language of the community in which research is being undertaken ... This not only relates to the mechanics of language but to the cultural values and concepts embedded in the language.

Sandy Ball

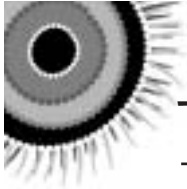
Other key factors identified were joint involvement throughout a project and the importance of using a research project as an opportunity for participants to learn and develop their own capacity.

Building and strengthening capacity of researchers as well as Indigenous peoples and communities through research is a vitally important factor to consider and involves considerable effort and due consideration in the planning of research. This includes capacity of researchers to ethically and effectively undertake research involving Indigenous people, and the capacity of Indigenous peoples and communities to understand, participate, take control, and have ownership of research (and the associated service, policy and practice) that they are involved in.

Yin Paradies







The workshop

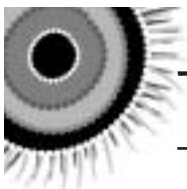
The workshop itself was held at Mirambeena Resort. Larrakia traditional owner Bill Risk welcomed everyone to Larrakia land.

Isaac Brown, Associate Professor at the Foundation for Aboriginal and Torres Strait Islander Studies at the NT University, opened the workshop. His gentle and perceptive welcome set the tone for the whole workshop. There had been some tension amongst participants – both Indigenous and non-Indigenous – about what the workshop might involve. Some of the non-Indigenous researchers in particular had doubts about the value of spending two full days on this issue, away from their ‘real’ work. (Though as one participant pointed out, if Indigenous issues aren’t the ‘real work’, what is?)

Isaac Brown presented a short extract from *Star Trek*, which highlighted many of the issues that would be central to the workshop, in a way that put people at ease. In the video clip, an alien species was conducting scans and in-depth analysis of crew on board the *Star Trek* vessel, without the crew’s knowledge or permission. The crew members were very angry when they discovered this, but the alien researchers felt it was quite acceptable behaviour. The alien species’ defence was that their behaviour was acceptable and in keeping with *their* right to know, and that such in-depth analyses would not harm the crew members. Clearly, the researchers were not aware of the potential harm that they could cause to the subjects on a non-physical level.

The first morning of the workshop involved two steps which began the movement of participants out of their normal comfort zones. The first was the presentation of a *Hypothetical* about research in Indigenous communities.

Introducing the session, Christine outlined the origins of the *Hypothetical* in the Harvard Law School. ‘It was created so that students had the opportunity to stand in the shoes of the people they might represent in the future. This process assists people to explore issues that may be difficult to address in day-to-day life. We hope this *Hypothetical* will serve to highlight some of the key issues pertaining to Indigenous health in Australia.’



The Hypothetical

This was the scenario for the *Hypothetical*:

It is the year 2001, and the excitement of pending federal elections has gripped Australian society. Early polls have shown that the Government will struggle to hold onto another term and in true knee-jerk fashion the PM is looking for answers. As is the usual governments practice, a team of expensive advisers are employed to turn the polls around.

One adviser has just returned from a stint as a community adviser to the Aboriginal community of Turkey Creek, it seemed that advising can be a lucrative pastime and it is his belief that there are votes to be had in Aboriginal issues. After three months of discussion and 1.5 million dollars in consultancy fees the advisers come up with a ten-point plan. One suggestion is that the PM says sorry, which is refused outright. Another is the release of a further 15 million dollars to continue the great tradition of research into the sick and infirmed Aboriginal population. It is the hope of the government that another big pay out will not only turn around 200 years of pain and loss, but also that someone else will find the answers so that they don’t even have to talk about it.

Appendix B has a full transcript of the *Hypothetical*.

The *hypothetical* was carefully considered, and sought to explore several key issues in relation to the conduct of research within the Indigenous domain.



These included:

- the need to explore the historical context of the state of ill health among Indigenous peoples;
- funding cycles and their impact on health research;
- the short-term perspective of policy makers who seek fast outcomes at the expense of proper process;
- the potentially negative impacts of seemingly well meaning research;
- the tendency for research to set the agenda on issues vital to the lives of Indigenous people;
- problems arising when Indigenous involvement in research proposals is tokenistic rather than collaborative;
- the importance of measuring the success of research from Indigenous perspectives
- the difficulties of conceptualising and implementing appropriate community involvement in research the way this affects the potential for community control of research; and
- the meaning of accountability in research, and how we ensure that accountability channels are built into research projects.

These extracts will give the reader a better sense of the spirit of the Hypothetical, because they show the enthusiasm and creativity of the people at the workshop.

Tony: Kerin, how are you? Look I hear there's some money lying around for some Indigenous research.

Kerin: Yes, it's true....

Tony: ...What are you guys looking for?

Kerin: Well my brief from the minister was fairly non-specific. Ultimately they are vote hunting. Something quick and with measurable benefit. Maybe something structural.

Tony: Are there any essential criteria?

Kerin: I suppose the usual submission buzzwords will do. Just mention capacity building, self-determination, culturally acceptable and appropriate services and perhaps some Indigenous employment... Basically you are not going to get any money without a few black faces in the study.

**Tony Barnes (playing The Evil Empire Builder),
and Kerin O'Dea (as the The Researcher),
from the Hypothetical**

Well, I've been explored, probed, lost more blood than a haemophiliac, fasted, measured, poked, ran on a treadmill for five hours, breathed into some machine that looked like my fridge. I have had samples from every bit of me taken; sputum, saliva, urine, bits of my stomach chopped out by a big black snake that they shoved down my throat, faeces, blood and cervical cells. I have even had my breasts squashed between two big cold plates. The last study they told me I had a high beta carotene level. You know what was strange, I don't even like carrots.

**Rowena Ivers (the individual
consumer in relation to research),
from the Hypothetical**



Rules of Engagement

Marr-yuwalkthirr: able to believe in each others' truth, able to see the truth in each other (Yolngu Matha) Kulinytjaku: to listen; Ngapartji-ngapartji: reciprocity (Pitjantjatjara)

The next step was the negotiation of Rules of Engagement for the conduct of discussion throughout the workshop. This placed the processes of communication firmly on the table. Presenters Terry Dunbar and Ely White explained that the setting of the Rules of Engagement was to allow participants control over how they wanted the workshop to be run.

Participants were asked to consider 'What ways of communicating make you feel comfortable?' and to 'Think about the positive things you would like to see in the way we communicate with each other over the next two days'. One non-Indigenous researcher questioned the need for the Rules of Engagement. 'Surely we are nice enough people not to need this session, I didn't realise the next two days were going to be so scary.'

Discussions certainly warmed up, to shape these Rules of Engagement, which themselves present a powerful and moving statement:

- everyone should respect the need for flexibility and the space to do what it takes to feel comfortable
- 'Gurram' – a Yolgnu word meaning 'a gentle way of communicating'
- everyone at the workshop is a peer and should be treated as such
- belief, respect and goodness, a belief that we all have something to contribute to each other
- 'Marr-yuwalkthirr' – 'able to believe in each other's truth, able to see the truth in each other'.
- a laugh and a joke and feeling at ease with one another will help make sure the workshop has the best possible outcomes
- everyone at the workshop takes responsibility for themselves and their own actions.
- The need to embrace the terms and meanings of 'Kulinytjaku' – a Pitjantjatjara term meaning 'to listen' and 'Ngapartji-ngapartji' – a Pitjantjatjara term for 'reciprocity'
- don't be too polite - people must be comfortable to express how they feel.
- make sure that we are honest about what we're doing
- focus on the real reasons why we are all here
- understand that constructive criticism is a valid tool in terms of the workshop objectives and don't take things personally
- we have to be able to feel comfortable enough to be open to one another
- sensitivity
- silence is acceptable and everyone should feel comfortable about staying silent if they want to.
- taking risks may be needed to get to where we want to go
- people should not be labelled during the workshop nor be judged unfairly by others



The discussion around the Rules of Engagement set a pattern for much of the workshop. It had introduced an element of uncertainty, framed in a way that allowed issues to unfold slowly and without being forced. The conversation was in keeping with the Yolgnu concept '*gurrum*', defined as a gentle way of communicating', which was introduced to the workshop by a group of Yolgnu researchers from Galiwin'ku. Issues could be explored from perspectives and in language not commonplace in the formal Western research context.





Group Work

One of the most significant elements of the workshop plan was that the participants would be split up into two groups: Indigenous and non-Indigenous. Each group was asked to consider examples of successful research projects in their respective cultural contexts, ie the Indigenous group to look at research in Indigenous communities, and the non-Indigenous group to look at research in non-Indigenous communities.

It was hoped that the process of splitting the groups into non-Indigenous and Indigenous groups would serve two main functions. Firstly, it was hoped that creating an environment of cultural safety within the workshop would allow researchers the freedom to speak openly and honestly about the issues that faced them. We believe that people working in cross-cultural settings can draw tremendous strength from the understanding and embracing of one's own culture. Only then can they work in an equivalent inter-cultural partnership. Secondly, it was hoped that through a process of self-reflection, the non-indigenous research group may be able to consider markers of success that were not specific to the work with Indigenous people and communities they had previously been involved in.

How the non-Indigenous group worked

I've only ever researched in other cultures, I have to dig deep to look at my own.

The non-Indigenous group appeared uncomfortable with the separation of the two groups. One researcher asked: 'I thought we were supposed to be working in partnership?' Another commented that: 'I felt totally bereft. I just wanted to be with the other group.' Another said they felt the separation denied them of an opportunity of talking with and learning from the experience and wealth of knowledge represented amongst the Indigenous researchers.

The task of looking for markers of success in research with non-Indigenous communities also seemed to concern and puzzle the group. They began by talking about a number of examples of mainstream Australian research: research into AIDS, evaluations of training, mosquito research, a study of nurses, and research into chronic heart disease. However the discussion was fragmented, and, participants repeatedly returned to broad issues such as 'outcomes based research', 'what defines success' and the relevance and purpose of research.

Other issues highlighted by the group included:

- Exploration of the conflict between community driven research and that directed by research and researcher agendas. The key successes of research into HIV/AIDS have not been translated philosophically or practically to address Indigenous issues. "Is research driven by questions of doing good or what is good for us [researchers]?"
- What defines and who decides what is 'successful' and important research. These points were strongly influenced by the context within which people lived and institutions survived.
- "Are outcomes more important than processes?" Perhaps the question could have also focussed on "is process an outcome in its own right?"
- The difficulties faced in bridging the gulf between evidence and positive action.

A number of the researchers commented on the difficulties that they had looking at their own culture, with statements like:

I've only ever researched in other cultures, I have to dig deep to look at my own.

We are not very good at seeing our own culture.



Being in the Territory so long now, it's difficult for me to see the markers of Indigenous and non-Indigenous.

A lot of non-Indigenous people will say they have no culture.

We are getting socialised into Indigenous ways too.

These comments contrasted markedly with another participant's observation that:

Working at the interface (of cultures) makes you very conscious of where you are coming from. You become much more aware of your own preconceptions ... At the interface we are then forced to look back on ourselves...

The group also discussed the scientific paradigm, or paradigms, and some of the implications:

We need to keep in mind that the strong beliefs that people have which shape their worldview are often not shaped by research or proof, for example, religion – there's no research that proves God exists.

A penny dropped for me yesterday. We believe that out of research will come better outcomes. But that is not necessarily a shared worldview.

A: *It (participation in research) is a matter of faith to do with Western rationality. You participate because you think the spin-off is going to be a good thing.*

B: *Scientists would say it's not a matter of faith, it's a matter of science.*

A: *It's a step of faith to believe that the paradigm of science produces truth.*

B: *Proponents of that paradigm don't see it as a step of faith.*

A: *I believe it.*

C: *The problem is where science leads you to one set of truth, and another takes you to another.*

D: *There are also lots of layers of faith within the scientific approach.*

A: *What causes illness? Different systems of knowledge come up with different answers. Different people find different answers unacceptable.*

B: *What's problematic for me is that other questions get pushed to a lower level because they lack relevance in the paradigm of science.*

E: *Why you choose this research, and why it's defined as successful, is inextricably linked to our paradigm. It may well be that the sorts of things that came out of that research are not valued in other paradigms.*

The non-Indigenous group spent very little of their time together talking about or planning their presentation. Two members of the group prepared models or summaries of the first day's discussions overnight, and presented these back to the group during the second morning. This provoked further discussion, and became the basis for the afternoon's presentation to the whole workshop.

At one point, during the second morning of the workshop, Ely White reminded the group that they were supposed to be discussing how research could be successful with non-Indigenous people. The following exchange took place:

Ely: What you were asked to do was to think about how non-Indigenous research is done with non-Indigenous people.

A: *We are not very good at seeing our own culture.*

B: *But why are we not very good at it? (general discussion on this)*

C: *We have brought our own values (ie developed through extensive work with Indigenous people) to this process.*

D: *I feel quite comfortable with this process.*

C: *We've described a successful model for research in the non-Indigenous community. It just happens to be one that would also be successful in Indigenous communities.*

Ely: *Maybe you should say, we haven't been able to do what was asked of us.*

Chorus: *But we have!!!!*

As this exchange shows, there were evidently some members of the group who agreed that they had been talking about the process of research within an Indigenous community. Others insisted this was not the case. However, if we look at the summary papers from which the non-Indigenous group made its presentations, one is headed with 'marr-yuwalkthirr', a word meaning to be able to believe in each other's truth, able to see the truth in each other.

There is reference immediately below this to 'science as one way of knowing', and 'recognition of other valid ways of knowing'. Are these issues that would be discussed in the first instance, if at all, in discussing research in mainstream Australian communities? These indicators suggest that, subconsciously at least if not consciously, the group did not succeed in retaining its focus on research in non-Indigenous communities.

Some people may have felt ill at ease in the non-Indigenous group. Several members of the group were clearly unhappy with somebody else setting the agenda for them; it was not the best way to 'work in partnerships'. Furthermore, several participants were unable to remain focused on the issues relating to research development within a non-indigenous realm. This was despite the fact that previous work they were aware of or had conducted was not aligned with indigenous concepts or paradigms, but reflected that of the non-Indigenous, institutionalised, scientific world to which they belonged.

The discussions and presentations of the work of the non-Indigenous group raised several questions.

- What does this reflect on the process and the outcomes of research activities for Indigenous people?
- What was the source of this unease? From where, or what, did it emanate?
- Why did the group find such difficulty in 'seeing' their own culture? What are the implications of this in relation to Indigenous research?
- Why did the group not identify their discussion of the scientific paradigm as a discussion of their own culture?

How the Indigenous group worked

It's about perceptions in the community. There are the Western perceptions, and Indigenous perceptions ... Can they learn ours and vice versa?

Mai Katona

The dynamics of the Indigenous group were very different to those of the non-Indigenous group. The discussions began with a degree of negativity from some researchers, that these issues had been discussed over and over and Indigenous people had tried to work collaboratively, but nothing had changed. The history of misunderstanding and mistrust between the research industry and Indigenous communities had continued, despite the adoption of ethics requirements and so-called collaboration. There was some feeling that going over the issues yet again in this forum was unlikely to bring about change.

The sense of openness and cultural safety, combined with the strong relationships of the group, allowed these views to be expressed and acknowledgment made of historical realities. It also allowed those with a more optimistic view to speak and to be heard. The discussion then quickly moved on with a sense of purpose. It was as if suddenly the whole group recognised that as a gathering of professionals, all talking and thinking in similar ways, they could have influence and bring about change.

They believed that properly focussed research - with strong foundations in communication and partnership - could bring about real change for Indigenous communities. They wanted to identify what they as Indigenous researchers could do to improve the situation, and how to build better partnerships with non-Indigenous researchers to achieve this outcome. There was a strong impetus to use the

workshop as a springboard for ongoing change.

This generated a sense of great excitement. There was a feeling of validation, of being free to speak and be heard, and a glimpse of the possibilities of change.

The discussions then moved on from analysis of research projects and issues to identifying the indicators of success and potential barriers to effective research. A central theme which emerged was the recognition that people draw different meanings from the same words, and that developing an awareness of those different points of view is essential to building better understanding and better working relationships.

It's about perceptions in the community. There are the Western perceptions, and Indigenous perceptions. ... Can they learn ours and vice versa?

Mai Katona

The group also identified the need to change not only ways of thinking, but also the action and behaviours which take place when working in Indigenous communities.

Attitudes are something you can change, but we also need to modify behaviour. There has to be a willingness to change. Every forum we go to we bring up these issues ... The responsibility for all of us is to reflect on what we are doing, we have to be more mature in our relationships.

Terry Dunbar

With these powerful objectives in mind, the group drew up a succinct diagram

showing some key values held by Indigenous people, the scientific/research community, and areas of overlap. The diagram and the discussions around it reflected the importance Indigenous people place on dialogue as a way to achieve understanding and move forward. It then formed the basis of the group's presentation when both groups came back together again on the final afternoon of the workshop.

As with the non-Indigenous group, these discussions provoked a number of questions:

- Why did this group feel so at ease?
- What enabled the shift from pessimism to optimism?
- What enabled the group to stay focussed on the job at hand?
- Why did members of the group find this process validating? What does this suggest about their day-to-day working relationships?
- What leadership strategies within the group made it so cohesive in its approach?



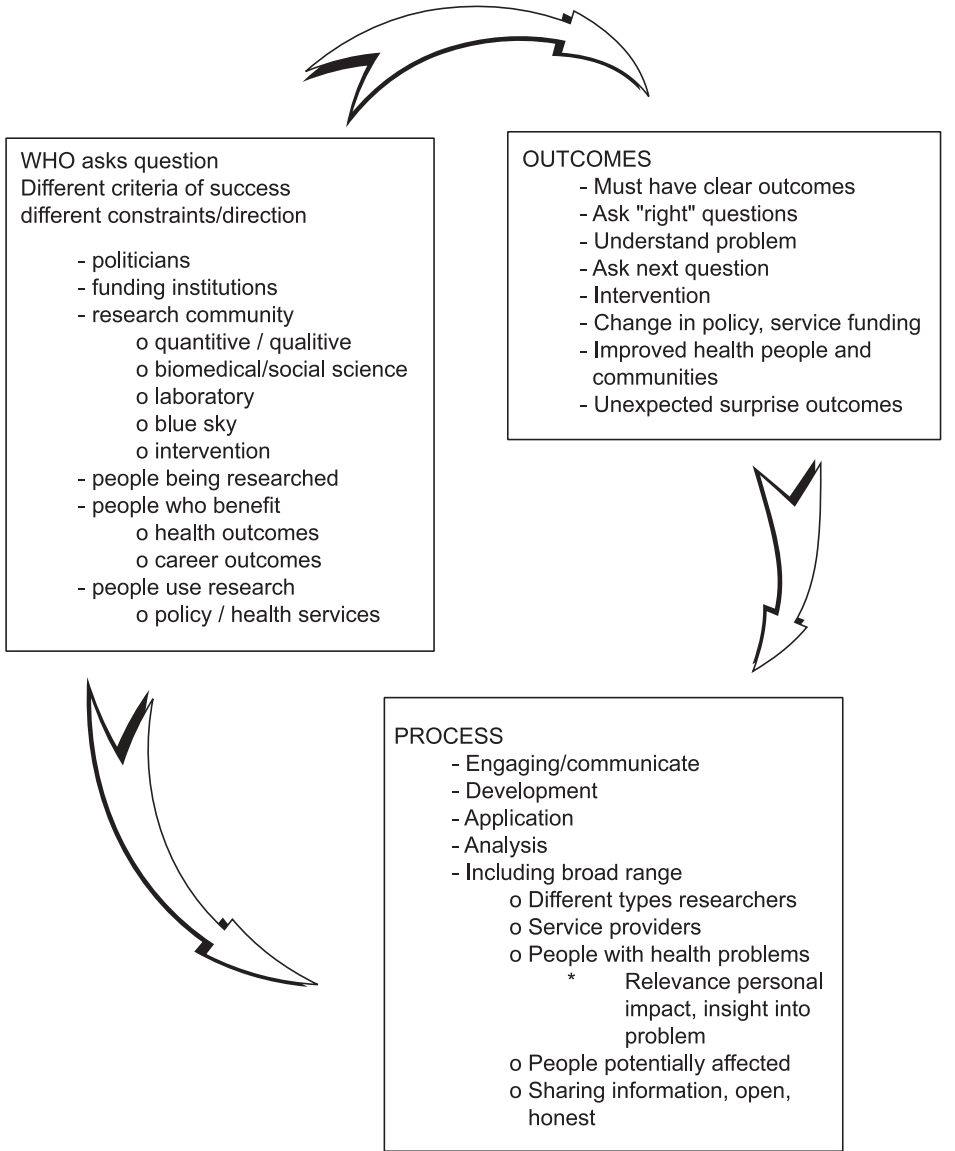


Presentations

Christine Connors and Sally Matthews presented their summaries of the first day's discussions in the non-Indigenous group.

Marr – yuwalkthirr Research is one way of learning and knowing; people believe this is a good/right way BUT – recognition of other valid ways of learning

Successful research depends upon:



Daniel McCaullay and Alex Brown gave the Indigenous group's presentation.



There were similarities between the summaries presented by each group, though they had emanated from quite different group processes. Both referred to importance of appropriate consultation, levels of control, appreciating both positive and negative outcomes, exploring the importance of accountability, the need to ensure an 'investment' in capacity, and the need to value and draw on the knowledge of other people. Similar issues and factors of success were identified in the responses to the questions circulated before the workshop. In summarising the discussion in the final session of the workshop, however, Alex Brown commented:

The list is very similar, but what we mean by and do with the words is different.

Discussion arising from the presentations

Both groups involved in the workshop displayed a great energy, a desire to do things right. In the case of the Indigenous group, this drive was to see real change occur in research practice leading to improvements in Indigenous health. For the non-Indigenous group, it was an eagerness to hear how those changes might be brought about.

What the workshop illustrated is that both groups 'know' the answers, at least intellectually. The responses to the pre-workshop questions, the similar language used in the presentations of each group, and the issues arising from the discussion show that both groups are able to identify key factors in improving research partnerships.

Some of the key factors identified were:

- The recognition and acceptance of one another's values, skills, practices and world view
- Establishing trust in one another
- Establishing relationships of genuine partnership throughout the research process
- Thorough and meaningful communication
- Accepting and drawing on existing structures, skills, resources and knowledge

These words and ideas are very familiar; they are 'the usual submission buzzwords' as referred to in the *Hypothetical*. They are very similar also to the Rules of Engagement set at the start of the workshop. The challenge is, to paraphrase one participant, 'to make the words live... to find a framework in which to work and make it live at all levels'.

Behavioural change

All of us have to become, and be genuinely reflective day to day in what we are doing. We need to look at what each one of us is doing to support or damage (partnerships). We have to put time into this, we all talk about it, but we've got to give time to do that and think about our own behaviour.

A theme touched on by a number of participants in the workshop was the need to change one's own behaviour.

We need to be able to open up an understanding far beyond what we currently have about the way that people think and behave.

Understanding collaborative practice is not something people know how to do. Understanding that takes a long time to learn, and it's very complex to do. We give people no training in that, but it's a skill you must have.

All of us have to become, and be genuinely reflective day to day in what we are doing. We need to look at what each one of us is doing to support or damage (partnerships). We have to put time into this, we all talk about it, but we've got to give time to do that and think about our own behaviour.

What the workshop illustrated was the gap between the conceptual or intellectual understanding of working collaboratively and the capacity to enact a truly equivalent partnership.

The challenge is, then, how to bring about congruence between our philosophical understandings of the process and construct of research involving indigenous peoples and the way in which indigenous peoples perceive, respond to and benefit from research activity.

Furthermore, how do we ensure congruence between Indigenous and research industry concepts of consultation and channels of accountability, levels of appropriate control over the process and outcomes of research, the development and understanding of capacity and alignment between the constructs of Indigenous intellectual property and rigour?







Intellectual rigour and accountability

If you don't have good process and don't think of rigour holistically, you can make a certain type of error that threatens the validity of the research.

At the outset of the workshop, and occasionally throughout, there was a contrasting of Indigenous intellectual and Western scientific/academic rigour. The Indigenous researchers emphasised that Indigenous knowledge and research had its own precision.

While the Western scientific paradigm was critiqued, particularly in relation to its appropriateness in research with Indigenous communities, the rigour of that paradigm was never actually questioned. However, if one considers the issues raised in this workshop, the 'rigour' of the Western scientific approach appears inadequate to achieve the objectives of the CRCATH to improve the effectiveness of research in contributing to Indigenous health.

The Indigenous group's presentation, in contrasting the scientific paradigm with the more holistic paradigm they were expressing, highlighted different understandings and interpretations of both rigour and accountability. Rigour is most often thought of as that embodied by the scientific paradigm. However, should rigour not also mean, doing the job properly, fully, thoroughly, correctly?

In contemporary Western culture, accountability is about money and measurement. In a more holistic view, accountability is about working to achieve genuine outcomes, and establishing checks and balances with the community to ensure that.

Both of these concepts are encapsulated in the Pitjantjatjara word '*kanyini*', a term mirrored in Indigenous nations throughout Australia. *Kanyini* means 'to have, to hold, to care'. It is a verb which 'reflects a commitment, a full engagement, vitalising again and again all that went before and all that will go after' (Keeping Company, 1996, 14)

Yin Paradies made the point that too much emphasis on academic rigour can bring about a separation from the broader comprehensive process needed to seriously address issues.

If you don't have good process and don't think of rigour holistically, you can make a certain type of error that threatens the validity of the research.

This is not to suggest a relaxing of scientific rigour. In fact, the opposite is required. Rigour must be intensified, heightened, broadened beyond its narrow definition within scientific tradition. It must become a true application of intellectual and lived thoroughness; what we might call a 'rigour of real life', which looks at the full picture, not just reductionist fragments.

This suggests that using an approach that draws on the knowledge and skills of many different people could enhance the rigour and accountability – and thus the effectiveness – of many contemporary research practices. Aboriginal kinship systems offer a vision of such a model.

Aboriginal society has no hierarchical structure; it can be thought of as an intricate, interconnected system of relationships, with each person having responsibility and obligation for someone else within the system ... The viability is maintained by a system of checks and balances. Each person within the kinship network has a specific role of guardianship and supervision for another designated person within the system. The network has prevented cliques being formed throughout the millennia so the knowledge is shared by all according to each person's level of understanding and responsibility. Kinship protocols also have a 'quality control' relationship where no one (undertakes any major work) without someone checking the accuracy of it.

Keeping Company, 1996, 40

This concept of checks and balances provides an ideal model for the development of effective equivalent partnerships. In such a model, each participant's role and what they bring to it is clear, and each has their own basis of power, stemming from their identified role and their relationships. No one's power is absolute – and each person is powerful. The system of checks and balances and shared responsibilities spreads the power throughout the group while at the same time ensuring quality control.

'We know what is needed, but not how to do it'

This workshop highlighted many things, but particularly that there is a divide between the knowing of what to do to work in partnership, and how to enact such a partnership.

What is needed has been set down, elaborated on and repeated many times.

Susan Napanangka Abbott illustrated the themes with her painting *Companionship*.

The painting reflects the country after the rains, with everything fresh and newly washed. All the colours are glowing to represent the vitality and vibrancy of the country as it renews itself after the long dry season. The red ochre represents the different Aboriginal communities and their essential relationship with the land, while the circle of gold paint is symbolic of the wholeness of community life and the absolute importance of functional, intercultural partnerships. The circle is surrounding and protecting the different professions as they work together...

People are working in equivalence and can be seen travelling to each of the communities to teach, to carry out different health programs, and to town to learn new skills. By working this way, the older members of the community can begin to trust new methods of doing things that will enhance their contemporary Aboriginal life. It is in these small groups that serious issues can be discussed in privacy.

Also, working equivalently brings about deeper friendships, enabling people to fully enjoy and value a different culture, both ways.

Christine Franks identified the following strategies for working in equivalent intercultural working partnerships:

*Give up perceived power positions which are inherent in a dominant culture
Listen and absorb new knowledge, to apply in future inter-cultural contact
Learn to stand back and observe what is happening, without overlaying the situation with your cultural baggage
Have the humility to appreciate another cultural viewpoint
Dare to give something of yourself at each contact – that is, not to be the enigmatic all-seeing all knowing professional
Assume equivalence of status within every working/social relationship
(Keeping Company, 1996)*

The challenge is to translate these from a list of words to a 'lived framework'.









Working in partnership

Working in truly equivalent partnerships is not an easy task. It requires a safe environment, and a solid foundation from which to open one's self up to listen and give. It requires skills to be able to explore the thinking of others, to recognise difference, and to juggle and take into account competing or paradoxical understandings.

Creating a safe environment in which research partnerships can grow and flourish is vital. Such an environment needs to take into account the needs and natures of each party involved, and find an optimal zone in which to meet and work. For example, what sort of environment is needed in which a non-Indigenous researcher can feel able to let down the guards of their discipline, and relate openly and honestly? What sort of environment is needed in which an Indigenous researcher is able to speak openly and honestly about issues and feel their knowledge and skills will be accepted for their true value?

In both cases, an environment is needed where the participants:

- Do not feel likely to be condemned
- Feel their views will be listened to with open ears and minds
- That difficulties, difference and emotion can be spoken about without fear of embarrassment and judgement
- Where one's vulnerabilities and weaknesses are able to be revealed and acknowledged

Critical to the creation of such an environment are relationships of trust and mutual respect. Such an environment allows space for participants to bring their commitment to a true engagement, true seeking and true rigour.

It is easier to create such a safe environment with individuals with a solid foundation in one's self – already able to listen, hear and give of one's self without fear of being judged – and with a high degree of congruence between their espoused and enacted theories and values. Even then, we may move in and out of groundedness, as our insecurities assail us, our energies rise and fall, or events overtake us.

Contemporary Western culture is only beginning to encourage the skills needed to work in truly equivalent partnerships, and most systems and structures still discourage them. There are many people who may never attain the capacity to work in such a way. There are encouraging signs, however, in the strong desire of many to learn. This learning requires deep self-reflection, opportunities to work alongside those who do have the skills, and time.

The task of effective research is thus clearly multifaceted. Research is much more than the science, in the same way as the writing of a paper is much more than merely a setting out of words. It would seem a key to developing improved practices in research in Indigenous communities is to build research teams which bring together all the diverse skills required for the job – whatever the particular job may be.

This includes those who carry out the advocacy, dissemination, logistical, accounting, and project management, as well as those who participate in the research and who make the partnership work. An appropriate analogy might be that of the making of a film, where professionals of great specialisation work in tandem with generalists such as producers – but all work toward a shared goal.







Conclusion

If we are asking the wrong question we are heading down the road of low impact research ... To ask the right question, it is important to ask the people first. If health problems are identified locally, there is more chance that research will be responsive to need. The findings are then more likely to have impact ... It is better science to get a view from the inside. Findings are more valid and are therefore likely to produce more realistic outcomes for communities ... Expert driven agendas ask the wrong questions and come up with less useful answers ... This kind of science needs to be questioned more rigorously.

John Grundy

This paper brings together the views of many different people. It has been a privilege to write it, to draw on the ideas of such vibrant, experienced, capable and committed individuals, and to feel the interplay and evolution of ideas throughout the process.

Perhaps it raises more questions than it provides answers, but this too has its own value. Ultimately, the process is dynamic and perpetual, just as the survival of Indigenous peoples through the millennia has been dynamic and ever-evolving. Already the CRCATH has set up a reflective action research program (the LINKS project) to identify indicators of successful research partnerships and to evaluate studies against those indicators.

These ways of working had begun before the workshop too, as this exchange illustrates:

- A: *Time always ends up being money.*
- B: *The cost-effectiveness of listening and thinking is enormous. It's very cost effective to do nothing for a few weeks at a time before you start doing things, and we don't value that.*
- C: *Somebody spoke about a meeting to do with a renal project, which delayed the commencement of the project, but the delay turned out to be beneficial. It added an appropriate time for development of the project which was useful.*
- D: *It's interesting how you framed that, saying the project didn't start. It did start, it was just the data collection didn't start.*
- C: *Yes, that's right.*

This point cannot be lost. The process of research with Indigenous communities, of establishing partnerships and relationships and of seeing the truth in one another, must be valued and accepted as an important outcome in its own right.

Furthermore, the development and conduct of research based on a methodology and worldview that may not be shared with the potential 'subjects' can have negative impacts. Not only can it devalue the culture and understandings of Indigenous communities, but it can also mean the research will lack meaning to those it is aimed to assist.

We must remain acutely aware of the feelings of disillusionment among Indigenous communities about the conduct, process and outcomes of research, from both historical and contemporary perspectives. There is a sense that it has been research conducted *on* Indigenous peoples, rather than research conducted *in partnership with* Indigenous peoples. If the process of research continues to avoid the opportunity to involve people, the resulting costs to communities remain unmeasured, and the erosion of communities' faith in institutions and systems can have costs outside of the sphere of quantifiable research outcomes.

We all need to keep thinking about and working on finding ways to make research work better for



Indigenous communities . Many of the participants commented on the value of the workshop. There was also strong feeling that these types of discussions must continue, through a range of forums such as workshops, Hypotheticals, debates, publications and discussions with colleagues, to sustain the momentum of change.

It shouldn't end with forums, however. During the workshop, Terry Dunbar signalled what is needed:

We're not going to go away with some wonderful model. You are influential people. Even if what you take away from here is to start questioning how you do your work, how you are going to challenge what happens...This is really about challenging our mindset, challenging our practices.

Terry Dunbar

References

Keeping Company: An Intercultural Conversation, (1996), Wollongong: University of Wollongong.





APPENDIX A

Responses to questions

Response 1:

1. Important factors:

Defining priorities for communities.

This is a difficult area as it involves consultation and many communities are over-consulted with no apparent benefit to them. However, developing a clear process which involves interested community members in setting priorities and researchers then being able to act on these priorities by developing proposals is important.

Ensure researchers have thoroughly searched for all previous relevant data in developing research proposals to reduce repetitive questioning, by discussion with experienced staff, using local and interstate networks.

Linking research results to outcomes and changes in clinical/community practice is important. This is still often the missing link, with long gaps between the research being conducted and results being disseminated. Even then, there is often no clear process to encourage changes in health systems to incorporate new knowledge. There is a strong research culture in the NT, but if the links between researchers and service providers were made stronger, this would provide incentives for health staff to adopt the results of the research.

One example is the epidemiological studies of invasive pneumococcal disease. Initial research in Central Australia demonstrated very high rates of disease, but there was little change in clinical practice following this study, except some adult vaccinations occurring in Katherine district due to the personal efforts of Jeff Hanna. After I studied the data in the Top End, this then provided the opportunity to plan a coordinated response, with a special surveillance database, making IPD a notifiable disease, successful funding proposal for project officers to conduct a NT adult immunisation campaign, successful lobbying by NT staff and interstate staff for Commonwealth funding of the vaccine. This has now made the issue of pneumococcal disease and vaccination campaign an integral part of the health system.

2. Ideal best practice

Obviously there is no such thing as we all make mistakes and learn continuously. The following principles, however, would contribute to improving communication:

- work with local community leaders and health staff to discuss proposals and plan an appropriate communication strategy;
- include community people and health staff (local and visiting) as research partners;
- try to integrate research and service activities whenever possible to reduce time demands on community members and be more efficient eg: ear research conducted simultaneously with school screening;
- use an interpreter to ensure meaningful discussion;
- allow enough time for what could, with frequent interruptions, be a long process; and
- link with a respected local person who will disseminate information appropriately.

A good example is the UPK Report: one of the best aspects of this study was it involved providing services to improve the houses at the same time as they surveyed housing problems. They also had regular public feedback in a number of formats which then generated further discussion and community action



3. Major impediments:

- researchers setting the agenda according to their own interests and expertise;
- competing priorities for community members;
- low levels of literacy limit meaningful participation in highly technical discussions;
- researchers having limited experience of remote area Aboriginal people and their communities and not being sufficiently aware of social norms of communication assuming that no questions or disagreement means consent;
- limited use of interpreters; and
- lack of involvement of local service providers and health service managers.

4. Keys to successful communication can be summarised to include:

- identify and act on priorities, which will often be social issues (alcohol, family violence) or health service issues, rather than technical matters;
- limit repetitive questioning and coordinate with other researchers and health staff;
- identify pre-existing knowledge and understanding and then build discussion from the point of shared understanding;
- promote active discussion to identify misinformation;
- recognise that community members (and often health staff) will be reluctant to challenge the expert view;
- work closely with local and visiting health staff and health services management;
- identify and work closely with respected people from the community;
- use interpreters
- establish relationships and allow long lead-up time for discussions; and
- provide some tangible benefit (eg help with health service delivery, community education or resource development), not just research results.

Response 2:

A. Most important factors

- relevance of what is being researched
- commitment to action, to using results
- a range of levels of research, e.g. from basic science to epidemiology to health services research
- not just 'health' (or illness) research, but wellbeing research too

B. Ideal

- come to shared understanding of priorities
- develop trust
- create and maintain partnerships
- develop skills
- create an action plan for the results

C. Impediments

- micro-focus of researchers (super-specialists can lose sight of context)
- lack of time, money, incentive and skill
- different world views (e.g. the importance of the 'scientific method' to many Western researchers)
- the nature of research (any one study is only a piece in a jigsaw puzzle--it's sometimes hard to know what it means until you have more of the puzzle completed)

D. Keys to success

- time
- trust
- basic level of shared understanding

Response 3

What in your experience are the most important factors to consider in seeking improved Indigenous health outcomes through research?

- The most important factor is getting the research question right. If we are asking the wrong questions we are heading down the road of low impact research
- To ask the right question, it is important to ask the people first. If health problems are identified locally, there is more chance that research will be responsive to need. The findings are then more likely to have impact.
- Many illnesses are socially determined. No one understands the social reality like the people who live in it. This is why it is better science to get a view from the inside. Findings are more valid and are therefore likely to produce more realistic outcomes for communities. Local people should therefore be setting the agenda for investigation of their own place (and participating in it). Expert driven agendas ask the wrong questions and come up with less useful answers. Less useful answers and less likely to produce real results at the ground level. This kind of science needs to be questioned more rigorously.

How would you describe the "ideal" (best practice) approach to communicating with Indigenous communities about research? To what extent have you observed this ideal being practiced? Example.

A best practice approach in my view is to start the research question from the ground up. That is, the research question should address a locally prioritised local health or social problem. Researchers are increasingly practicing this ideal. This is less the case with health practitioners. I have seen researchers assist communities with a health needs assessment and then follow this up with an action research project that addresses the prioritized problem. Although the ideal is far from perfect, it is a big improvement on expert driven research. It results in some realistic problem solving projects that engage or employ local people in the leadership and conducting of local projects. I have seen this in relation to diabetes prevention and nutrition projects with some tangible results for communities.

What do you think are the major impediments for successful communication about research?

- Community perception of the self interested nature of research and researchers
- Community fear of being tested by outsiders
- Researcher perception that non experts cannot research to the same standard
- The nebulous mystical language of the research community, and its failure to be translated into everyday language that is meaningful to communities
- The obsession of the academic community with peer reviewed journals in contrast to the neglect of effective communication to beneficiaries in community reports.

What do you think are the keys to successful communication about research?

- Starting from the ground up
- Local leadership and participation in research
- Means of communication (community reports or peer review publications?)
- Trying to embed a culture of research and evaluation in health and development practice
- Demystifying concepts and language. If understood by the beneficiary, the use of the research is enhanced.

Response 4

1. What, in your experience, are the most important factors to consider in seeking improved Indigenous health outcomes?

- A long lead in time to develop relationships of rapport, trust, interest and mutual respect;
- Pre evaluation of all foreseeable aspects of a proposed project seeking improved health outcomes in consultation with key/identified Indigenous people;
- Lots of talking and hunting with Indigenous people in a true effort to truly understand their world view, issues of concern; availability of local human resources with skills, expertise, and knowledge (cultural, and Balanda) that will assist with the project;
- No fly in/out on same day;
- Indigenous ownership of project activities;
- Balandas being prepared to accept leadership and guidance from Indigenous peoples;
- Indigenous peoples identifying, through their clan structures, personnel who are best placed in their community to work on projects; and
- Mindfulness that ownership and control do not slip back into Balanda hands; careful use of language;
- Remote access to web/intranet; and
- Establishment of “virtual” chat rooms for researchers in the field, this would promote discussion and support and prevent field researchers feeling “isolated” in their studies.

2. How would you describe the “ideal (best practice) approach to communicating with Indigenous communities about research?”

- Canvassing/consulting with as many indigenous peoples as possible;
- Use of public forums to gauge community interest and opinions (community council meetings, Tidy Town Forums);
- Involving Indigenous peoples in the research process;
- traditional clan structures – discussion with all/as many *mala* leaders as possible; and
- listening to what the community has to say.

3. To what extent have you observed the “ideal” being practice in Indigenous research projects that you have undertaken/been involved with/observed? Please provide an example

- Yalu
- Healthy skin consultations
- Katherine West second (?) Evaluation
- Alice Springs project – the TREE ONE can’t think of the name – but was showcased at the annual learning conference
- Irrerkelantye Really do not know a lot about this project but it would seem to focus on guidance and importance of Indigenous knowledges, practices and issues identified by indigenous peoples themselves.

4. What do you think are the major impediments for successful communication about research?

- Assumptions;
- Funding requirements may skew or alter the aims/goals of the project;
- System requirements – written plans and reports, employment issues;
- Timeframes; and
- Lack of co-investigators working in the field as support for Indigenous co workers.

5. What do you think are the keys to successful communication about research?

- Dissemination of project information back to community, in language;
- Flexibility of research information format – visuals, video, audio, maps, drawings, input by participants as information is being gathered eg map created by Sam & Noni during the Katherine West evaluations;
- Accepting that time has different meaning to Indigenous peoples and being able to accommodate, accept, and work within their time parameters.
- Acknowledging and accepting guidance from Indigenous peoples themselves on how best to communicate about research.

Response 5

A. What, in your experience, are the most important factors to consider in seeking improved Indigenous health outcomes through research?

The important factors I think are to do with the processes of planning and conducting the research and looking at the potential uses of the research from the outset.

- That all stages of the research are undertaken jointly between the research organisation and the community/organisation, ie the development of aims and objectives, the methods used, collection of data, analysis and reporting.
- That different levels of the community/organisation are included and involved
- That research has practical and useful applications that are transferable to other communities/organisations
- That sufficient time is taken for two way learning – outside researchers learn the ways in which the community/organisation works, and training is provided if needed for community members or organisational workers about the research purpose and methods and applications. Also that there is sufficient time to ensure that each partner understands the context of the research
- That the research is flexible in its approach and genuinely incorporates indigenous frameworks of operation
- That the research outcome is not only a report for publication but that there are mechanisms built in to enable application if possible eg “how to” manual, materials for training or use in future.
- That there are protocols developed for methods, implementation, use of information, publications and mechanisms for conflict resolution.

B. How would you describe the ideal (best practice) approach to communicating with Indigenous communities about research? To what extent have you observed this ideal being practised in Indigenous research projects that you have been involved with/observed?

The communication needs to happen all the way through the research, not only in relation to the results. Many of the above comments are also relevant to the issue of communicating about research. The following comments are about a project in which I was involved in an urban Aboriginal Medical Service (AMS) in which staff spoke English as their first language. The comments relate largely to the processes of carrying out research rather than the communication and use of research results.

I was involved in a research project within an AMS in which the AMS and three university research bodies combined to implement a before and after study. There was a lot of discussion between the AMS management and the research bodies about the project and it was agreed to go ahead with a Steering Committee including representation from the AMS management, AMS Board, and each of the research bodies. The partnership between the bodies worked well and was one of the most successful aspects of the project. There were a number of factors which contributed to this:

- First, both management people at the AMS and the researchers were committed to trying something new in this area, even though the AMS already had a number of programs in place at the local level. When it became clear that a number of Aboriginal Health Workers were not happy with some of the research processes, these were changed. This meant substantial changes to the research design, but this was important in terms of AMS control of the project and the willingness of the researchers to listen to the most appropriate ways of undertaking the research.
- Second, the AMS had control both of the project budget and the hiring and employment of the project officer, who worked full-time and involved herself as much as possible in the daily life of the clinic. This meant that there was consistent, ongoing interaction and communication with staff at all levels about how the program

should be implemented. Without the level of day-to-day involvement and relationships that the project officer had with the staff, the project would not have gone past the initial stage.

- Third, the project collaborators developed and signed a Memorandum of Understanding (MOU), based on one successfully used by another Aboriginal Medical Service. Under the MOU, the signatories agreed on who would receive the grant and manage the funds (the AMS), and the study design. They also agreed on who would collect, code, and hold copies of the client data, and under what conditions.

For the quantitative data, all processes were conducted by the AMS, with de-identified data only being transferred to the one research body that was responsible for analysis of data. The qualitative data on the other hand were collected, transcribed and stored by the university team members.

The signatories agreed that the results of the project would be made available “in an appropriate format to participants and stakeholders at the AMS”, and “prepared for publication in the scientific literature”. A publications review committee with two AMS and two research organisation members was agreed, the role of this committee being to “authorise and review publications and presentations arising from the trial”.

A final clause agreed that should a dispute arise which could not be resolved by the project partners an independent mediator would be asked to mediate. Feedback to those involved within the AMS was face to face in meetings and in report form.

The MOU was important because it clarified issues to do with rights and responsibilities, including in relation to data and publication, before the project began.

In addition to the partnership processes, the research had clear potential to influence the practice within the AMS and to be transferable to other AMS. So the possible benefits could be seen from the outset. It had practical application and was not just research of an abstract nature for publication only.

Nevertheless, there were parts of the communication which were less than ideal. In particular, in the planning of the project, there was a lot of discussion between the researchers and the management and Board of the AMS, but staff and clients were not clear about the processes. These were the people implementing the project and more time should have been spent by the researchers in going through these processes in detail prior to the project officer being employed. Once the project officer was employed there was a lot of time spent talking through the project, but this could have been done earlier.

C. What do you think are the major impediments for successful communication about research?

- Language – if the researchers don’t speak the first language of the community in which research is being undertaken or the languages of the community with which the research results are being discussed. This not only relates to the mechanics of language but to the cultural values and concepts imbedded in language.
- Views about health – if the researchers are not aware of how aspects of health and well being are conceptualised within a community
- Relationships – if the researchers are not aware of factors affecting relationships within families, between skin groups and between families
- Priorities – researchers may be task driven rather than spending time developing relationships with community people.

Many of us in THS lack this range of knowledge and skills. Sometimes this lack can place substantial demands on community people and Aboriginal Health Workers to bridge the communication gaps.

D. What do you think are the keys to successful communication about research?

Understanding of all the factors above. As many of us don't have the language skills and knowledge that would be ideal, it is all the more important to work in true partnership with the community. Communicating research results in general is a skill that does not necessarily manifest itself in articles in research journals. I think that this is an area in which we need a lot more practice and training to do well.

There is little research in the area so the CRC workshop is really valuable. Many people in the NT of non Indigenous background who have not been here for a long time do not speak any Indigenous languages – so we must find ways to try to communicate within this limitation. Richard Trudgeon's book points to the pitfalls in this and sometimes I am not sure of how well or poorly I am communicating. In terms of communicating health data. I try to use appropriate graphs and explain these clearly, but doing this within the limited time in a council meeting for instance is not satisfactory. I think it needs more time. Working in with Aboriginal Health Workers or other cultural brokers helps this process, but is not always possible or appropriate.

I don't think I've answered the question – I look forward to this being discussed in the workshop

Response 6

What, in your experience, are the most important factors to consider in seeking improved Indigenous health outcomes through research?

Appropriateness of the research conducted. How can the results be translated into services, policy, practice. Research must include recommendations and feedback to the people researched and the wider Indigenous (and non-Indigenous) community.

The need to further integrate service delivery improvements and policy development as a necessary result of research findings. Research should be informed by the needs of the Indigenous community and also to a lesser extent government, and service sectors. Research advocacy as a part of, or related to research transfer. This involves knowing what efforts are most effective and efficacious and advocating for these activities to service providers, policy-makers, communities etc.

The need to recognise and attempt to overcome the structural and systemic bias that works against intercultural collaboration in research in imposing the processes, needs, accountability, methods, procedures, criteria of quality, value, and recognition of the dominant culture hence reducing the effectiveness of research for and by Indigenous people using Indigenous ways.

It is important not to impose dominant cultural ideals onto Indigenous people in general and especially when conducting research. Even well-meaning people can make mistakes in insisting that something be done to make things 'fair' or 'equal' with what occurs in the dominant culture. What is required is the same level of respect, consideration of and level of communication with Indigenous peoples' needs, as defined by them, which is the underlying ideal behind the 'fair' treatment that researchers are attempting to achieve.

There must be considerable time set aside to bridging cultural gaps and establishing clear and informed understanding for researchers on the views and ideas of the Indigenous people involved in the research and vice versa. This includes the recognition, valuing and utilisation of Indigenous knowledge and communication skills.

High levels participation in, and control over, the research process is essential. This can be through avenues such as employment of community-based researchers, flexibility in employment options and use of participants' language at all stages from data collection to dissemination of findings

Ensuring adequate resourcing to respond to the inevitable but unpredictable changes inherent in a genuinely participatory research. This includes flexibility in funding and timeframes to allow for changes. This may involve time-frames that incorporate down time for cultural activities etc and requires a recognition that the time-orientated thinking and organising of the dominant culture is a particular ethnocentric western/European concept. Resourcing for projects should include lead-time, capacity strengthening, clear objectives & evaluation criteria and on-going, long term onsite support.

Building and strengthening capacity of researchers as well as Indigenous peoples and communities through research is a vitally important factor to consider and involves considerable effort and due consideration in the planning of research. This includes capacity of researchers to ethically and effectively undertake research involving Indigenous people and the capacity of Indigenous peoples and communities to understand, participate, take control, and have ownership of research (and the associated service, policy, and practice) that they are involved in.

How would you describe the “ideal” (best practice) approach to communicating with Indigenous communities about research?

Listening to what people in the community have to say is probably the most important part of communication. However it is equally important to first explain fully and in detail about the research that is being considered.

The research concept should be communicated to community councils, heads of families and other appropriate persons in communities. This process takes time and effort and should be given an high level of regard as part of the research process.

Considerable preparation should go into determining what information will be communicated and how including possible use of visual aids, props, appropriate written material etc. The possible benefits to the community (and others) of the research should be clearly understood by the researchers and then just as clearly explained to people in the community without overstating the case and whilst being open and honest about all aspects of the research.

To what extent have you observed this “ideal” being practiced in Indigenous research projects that you have undertaken/been involved with/observed? Please provide an example.

Ideal communication is by no means easy in practice and in fact requires a lot of practice in any context. I have observed good communication being practised with varying degrees of success in a number of projects run by the CRCATH.

I think in the population project that I was directly involved with we achieved a good level of communication. Other projects that I believe have done well in this regard are the Yalu project, Health and Education Exploring the connections & Learning lessons: Approaching Indigenous health through education, the rethinking compliance project and the Evaluation of an Aboriginal Empowerment program project.

What do you think are the major impediments for successful communication about research?

Difficulties in bridging cross-cultural divides, prejudice, discrimination and racism including systemic racism and bias where systems and structures impede the mechanisms for effective communication through imposing dominant culture beliefs and ideologies.

Insufficient time, resources, and effort allocated to communication about research. A lack of recognition by the scientific and general communities of the difficulties in communicating well in cross-cultural contexts and hence a de-valuing of this effort (ie systemic bias).

What do you think are the keys to successful communication about research?

(Refer to responses for question 5 B)







APPENDIX B

Indigenous Research Workshop April 2001

Darwin, NT

Hypothetical Scenario

Introduction:

The basic premise of the hypothetical scenario is to explore several key issues around the philosophy, process and outcomes of indigenous research that we hope to cover during the workshop.

I thank you for your interest in being involved, as I believe this workshop could signal a vital step in addressing some of the disparities experienced in Indigenous health. It is my contention that we should not only look at health as an outcome, but more importantly, we should be key players in establishing a process by which western ideals, agendas and frameworks can be held accountable to the conduct of research among Aboriginal communities. It is hoped that this workshop will act as a trigger point to a much larger process of ensuring that traditional values are validated and protected through the very process of research activities. Furthermore we hope that this workshop will explore some of the barriers to indigenous development, particularly as it relates to research. Ultimately, we wish to see that institutional racism in all of its manifestation, whether overt or unintentional, are no longer a part of the research frameworks of academic, governmental or community based health care researchers and providers.

The Panel Members:

You have been asked for your input for several reasons, but largely because of the personality we hope you will bring to the discussion. Characters have been based on both real life and fictitious players in the research and political fields. There is certainly room for improvisation in these characters, and in fact the more you can bring to the discussion the better. I will outline some key points that I hope are covered during our interplay, but the sky is the limit. I will detail some specific dialogue between characters, but these are just to ensure that several key points are not lost. These issues will remain as the thread throughout the workshop (or at least that is the intention).

Jacko Angeles: 'Prime Minister of Australia'

Rowena Ivers: 'Dora from Double Bay'.

Represents the individual/consumer in relation to research

Tony Barnes: 'The evil empire builder'.

Established both his name and professional stature on the back of Indigenous research. Owns a large pharmaceutical company as well.

Maria Scarlett: 'The Legend'

Well regarded by both Indigenous community and research field alike. Has established a process for research that encompasses the values we hope to highlight as important in Indigenous research.

Mark Mayo: 'Bennelong'

Used and abused by institutions as the token Aboriginal involved in research.

Kerin O'Dea: 'The researcher' (non-Indigenous)

Extensive experience in research.

Daniel McAully: The Indigenous researcher



Setting the scene:

It is the year 2001, and the excitement of pending Federal Elections has gripped Australian society. Early polls have shown that the Government will struggle to hold onto another term and in true knee-jerk fashion the PM is looking for answers. As governments do, a team of expensive advisers are employed to turn the polls around.

One adviser has just returned from a stint as a community adviser to the Aboriginal community of Turkey Creek, it seem that advising can be a lucrative past time and it is his belief that there are votes to be had in Aboriginal issues. After 3 months of discussion and 1.5 million dollars in consultancy fees the advisers come up with a ten-point plan.

One suggestion is that the PM says sorry, which is refused outright. Another is the release of a further 15 million dollars to continue the great tradition of research into the sick and infirmed Aboriginal population. It is the hope of the government that another big pay out will not only turn around 200 years of pain and loss, but also that someone else will find the answers so that they don't even have to talk about it.

AB: PM Howard, thank you for your time.

I have heard rumours that the Federal Government will be releasing 15 million dollars within the next 3 months for indigenous research?

Jacko: That's correct. We saw the need to address the growing disadvantage of Indigenous Australians.

AB: Isn't 3 months a pretty short time frame for proper discourse and consultation, particularly with the Indigenous community?

Jacko: We need answers and we need them now. Furthermore there is an election coming. The Opposition would not look upon Aborigines as kindly as this Government.

This Government is clearly committed to Aboriginal affairs and what better way to show it than with 15 million dollars of assistance?

AB: Is it a response to the growing and genuine interest displayed by the average Australian in true and meaningful reconciliation?

Jacko: Clearly we are representatives of the people. If we weren't to listen to what people are saying, then we should not be office. Clearly the Aboriginal issue isn't going to go away.

AB: Well, maybe yes, maybe no. Colonisation has tried really hard to see to that. Syphilis, small pox, influenza, genocide were pretty successful, but it seems the new weapon is alcohol and welfare dependence. Chronic diseases continue to climb. When do we say that enough is enough?

Jacko: That's unfair. I wasn't even around then. And my ancestors didn't arrive until the 1940s. This Government has always been committed to reconciliation and the future. I am not here to rehash the past.

AB: So, Prime Minister, how is this money to be spent?

PM: Clearly we need to be mindful of the needs of the Aboriginal community. My interests do not lie with research issues. In fact, this is only part of our ten-point plan to win the Aborigines back. That's why we have set up an expert advisory committee.

AB: Kerin O'Dea, you are approached by representatives of the Government to be head of this advisory committee. You are summoned to Canberra from your small but functional lab within the Ungrateful Native Department of the University of Adelaide.

You believe this to be an enormous honour, which results, you believe, from your groundbreaking work on the correlation between skull dimensions of the tribes of Central Australia and their inability to adequately care for their children.

Kerin: That's unfair. We clearly demonstrated a linear relationship between frontal bone thickness and inappropriate child rearing. If it wasn't for this study, thousands of Aboriginal children may never have lived long enough to learn English, Christianity and how to maintain a clean and tidy house. In fact, recent analysis has suggested that the removal of children from the Pitjantjatjara Lands was more cost-effective than the Adelaide to Darwin railway.

AB: So forced removal of children was an exercise in health economics research?

Kerin: I mean that the impetus for the study was the fact that health services could no longer cope with the premature and preventable death of Aboriginal children. What else could we have done? Ultimately the outcome had the desired effect. We saved Aboriginal kids.

AB: But at what cost?

Kerin: A cost that was deemed acceptable.

AB: Acceptable to you alone perhaps.

AB: Tony Barnes, you have a long history in Aboriginal research, what is your view on studies that lead to worse outcomes than anticipated?

AB: Maria Scarlett, have you any concerns for such approaches that don't take heed of the potential negative impacts of seemingly well meaning research?

Maria: We as researchers must remain acutely aware of what effect research findings will have and on who these effects will impact both in the short and long term..

Kerin: How was I to know what would be done? I can't be held responsible.

AB: Despite the fact that the 'ground breaking' work you conceived had significant negative effects on the indigenous population of Central Australia, you receive an audience with the Minister of Health and are charged with establishing and implementing the use of these funds. How do you proceed?

Maria: Maybe someone should ask the Indigenous community what they deem as important and necessary.

Jacko: We would be uncomfortable with that sort of approach. How could we expect people with no education, no understanding of the intricacies of health service policy and research agenda to have any comprehension of these issues?

AB: Mark Mayo, do you have any concerns about asking Indigenous communities about their own agendas?

Mark Mayo: Not at all. You have to understand the tremendous insight and strength that Indigenous communities have. It would be stupid to dismiss Indigenous answers to their own problems. The road to destruction has been paved with paternalism and beneficence.

AB: Despite the useful suggestions of the research and general communities, it is decided that the best way to proceed would be undergo the usual 'tender' process.

Tony Barnes, you hear the whispers of money for more research and the dollar signs start spinning in your eyes. 15 million dollars will go a long way to establishing the ivory tower of Indigenous research you have always dreamed of. You believe that your track record is second to none, and that you are ideally placed to best meet the needs of the Government.

It just so happens that Tony is a good friend of Kerin O'Dea. In fact they collaborated on the first examination into the mathematical modelling of genetic cleansing of Indigenous children.

Tony, You give Kerin a call to check out the possibility of attracting some of these funds.

Tony: Kerin, how are you? Look I hear that there is some money lying around for some Indigenous research.

Kerin: Yes it true, where did you hear that?

Tony: On the grapevine. You know that I have ears all over. Look, we would be very interested in putting something together. What are you guys looking for?

Kerin: Well my brief from the Minister was fairly non-specific. Ultimately they are vote hunting. Something quick and with measurable benefit. Maybe something structural.

Tony: Are there any essential criteria?

Kerin: I suppose the usual submission buzzwords will do. Just mention capacity building, self-determination, culturally acceptable and appropriate services and perhaps some Indigenous employment. It would be advisable to add some essential positions within the submission that include Aboriginal people. Basically you are not going to get any money without a few black faces in the study

Tony: That sounds fairly easy. Our submissions ooze that stuff. In fact we invented the terms. We'll put a few Aboriginal faces in the proposal and it will be sweet. How does a National Institute of Indigenous Research sound?

Kerin: Sounds good. Let me know when the submission is ready. I will fast track it.

AB: Tony, you mentioned a few Aboriginal faces. Anyone in mind?

Tony: I would definitely give Mark a call.

AB: Mark Mayo, you have often been involved with research conducted by Tony and his associates. You are at home watching the football, when you get a call from Tony.

Tony: Mark, how are you?

Mark: Good, what's up?

Tony: Look Mark there is an exciting possibility of setting up a centre of excellence for Indigenous research. We need some of the skills and inter-cultural expertise that you can offer to make it a possibility. Can I interest you in becoming involved?

Mark: I don't know Tony, what exactly are you up to?

Tony: Well it's all a bit vague at present. Basically there is 15 million dollars lying around. It's a tremendous opportunity to do the things that we have always known are needed. We can't let this chance slip, but we would not be in a position to make a really good go at it without your contacts and experience.

Mark: Have you spoken to any of the Indigenous communities or elders about what they want?

Tony: Not yet. Its more important that we get the submission in fast. We can work on the specifics after we get the money.

AB: Mark, you are concerned about the lack of community consultation, but decide that without your involvement, the submission may lack any Indigenous perspective and involvement. You swallow your concern and start to think through Tony's offer and some actions that may be worth considering.

This is not the first time that you have had similar concerns, is it Mark?

Mark Mayo: No, it's not. One particular experience was in a study on kidney disease in several remote communities. I felt that my involvement was just brown washing the submission so that the money would come through.

They never listened to much of what I had to say. I was just there to make the study look a bit more Aboriginal. When I raised concerns about the process and outcome of the study, I was told that any changes to a more 'Aboriginal way' would jeopardise the validity of the results.

AB: What advantages did having an Aboriginal in the team have for the research?

Mark Mayo: Being the 'insider' meant that I was able to get information that the non-Indigenous researchers couldn't get. Being an insider meant that the people I was interviewing could check me out, could connect with me on a level far and above normal research boundaries. But it also meant that I owed something to those involved that the other researchers wouldn't allow me to repay.

It put me in an awful position, a position that I could never fix.

There are clearly pressures of being an insider- from external sources, within me and internal to the community. Institutional agendas don't even appreciate these pressures.

AB: Daniel, have you ever been put in similar situations?

Daniel: I also found real problems when doing my PhD. I developed significant concerns with the growing problem with an Indigenous researcher undertaking academic pursuits in Indigenous communities. The whole process is based within a non-Indigenous framework. The conception, conduct and evaluation of research don't align with Indigenous ways of working or thinking. When it came to evaluation, what the community thought was a good outcome was seen as bad by my supervisors. Conversely, what my supervisor deems as a good outcome may be bad for the community because it may not adequately address the problem.

If I can't measure benefit the same way as the community does, then evaluations from an institution may put me at odds with the community. It makes me look bad in their eyes.

Unfortunately though, I had to pass the tests to continue to do the things that I want to do. I just have to accept the pressures of who I am and who I represent.

AB: So what effects did these additional pressures have on you?

Daniel: If I measure something and don't do anything about the problem then I lose face with the people who have put their faith and trust in me.

Mark Mayo: I found the added responsibility too much to take. I had to turn to grog as an escape, to try and forget. My bosses just never understood the fact that I can't represent all Aboriginal interests, that I don't speak on behalf of all Aboriginal people, that I don't know or am not privy to all information for all communities.

AB: Daniel, do you find that researchers expect that you fill the role as a kind of guardian of Indigenous concepts/cultural sensibilities, as an expert in all things Aboriginal?

Daniel: Absolutely, but more so, it's as if that they expect that with me in the team, it won't fail. That they have guaranteed success. It's pretty hard to live up to those expectations.

In fact sometimes it's impossible. It feels sometimes like I am being set up to fail. I don't think anyone means that, but it feels that way.

AB: Maria, Mark just happens to give you a ring to discuss some of his concerns. You have long stood back and watched the dollar hunters fight for the last few cents of research money.

Do you have any advice for the unscrupulous?

Maria: I think that the importance of Indigenous involvement cannot be overstated, but we must always remain aware of setting up communities and Aboriginal researchers to fail. The expectations are often too high.

Furthermore we have to be aware of the importance of not overselling the likely benefits of research into Indigenous communities, that sets up expectations that can never be met and leave a bad taste in people mouths. We may often overstate what we can achieve so that we guarantee community involvement.

AB: What has some of your research in remote communities borne out?

Maria: Ideally, the development of Indigenous research should be about creating a climate of opportunity for research that has direct benefit for Aboriginal people and researchers alike.

We found that research that empowered those being researched had the best outcomes. The training of Indigenous researchers, development of skills, knowledge, opportunity and authority of Indigenous community members is essential. It allowed communities to ask the questions that they believe need answers.

We found that this meant that our research agendas included a vision for Indigenous development that incorporates the important issues for Aboriginal people. Ultimately we hope that through these steps, Indigenous people would no longer be passive recipients of research.

AB: Do you think that placing Indigenous research within an Aboriginal perspective makes life harder or easier for researchers?

Maria: At first it may seem harder, but ultimately the engagement of the community and the building of strong ties between researcher and community makes getting things done easier. In one of our projects, we couldn't get any compliance until we changed the way we did things.

I am now convinced that the holism of Indigenous health should be reflected in Indigenous health research. It should be conducted within an Indigenous framework. Not only in process but also in outcomes. We have found that it is vital to address the entire issue within its appropriate context or its benefits to Aboriginal communities suffers.

AB: What about when it come to releasing the results from you work?

Maria: We need to be happy to understand that the control over knowledge is that of the community, not us. Our experience is that this helps to foster two way respect and regard.

Tony: All these touchy feely ideas are all fine and dandy but without academic and methodological rigour, our work will never be accepted by our peers and funding bodies.

AB: Daniel what do you think about that?

Daniel: We seem to be forgetting that the primary audience for the research is the people being researched, not one's academic colleagues.

Daniel: Clearly there is an academic, financial and institutional benefit from the sickness of Aboriginal people. With that comes a tremendous responsibility to Indigenous Australia. Are researchers prepared for those responsibilities?

These responsibilities to the community extend far beyond strict methodology. At first there may be consent, but there is then an unwritten contract with the community. We found that the community engaged in the research proposal assume that there was some tangible benefit for them by way of positive social outcome or the resolution of the problem. Few researchers are in a position to bring about such change and fewer would admit to it.

AB: What did the community look for in researchers?

Daniel: Commitment to Indigenous people and issues, trust of the community, cross cultural competence, commitment to the obligations, liabilities and responsibilities that are an integral part of Indigenous research.

AB: Maria, what would 15 million dollars mean to you and what would you look at doing with the money?

Maria: We would be likely to attempt to attract some of the funding in an effort to adequately assess and establish the community priorities in research. I think we would also have to add some approach to conceptualising and trailing research methods that do correlate with community expectations, methods and outcomes.

We would look at issues like consultation, community involvement in the conception, coordination, participation in the activities of the research, compilation of data, evaluation, and ultimately the dissemination of the findings.

AB: Mark Mayo, have you ever been involved in any such research, whereby the community was an active participant through all aspects, from conception of the research priorities to dissemination.

Mark Mayo: No I haven't, and I would be surprised if it ever received funding. It is just too radical.

One thing people don't seem to understand is that not all information can be passed on in journals and to those not in a position to receive information. It seems it was always the researcher who decides what information is acceptable and what is not rather than the elders of the communities who have been researched. I was always the bunny responsible for going back to the community and telling them what the big researchers had found, and it was always me who had to tell them that we were finished here and would not be back. I was lucky to have gotten out of some of those communities alive.

There has to be some correlation between the concerns of the community and the agenda of the researcher something like a goodness of fit model.

Tony: It's irrelevant. We don't set the priorities, the funder does. We have an obligation to the funder to deliver what we told them we would do.

AB: But you also enter into a contract with the community.

Tony: We don't sign any contract with any community.

AB: So that absolves you of all responsibility to the community.

Tony: There is no law that states we have to ignore the funder in preference for the community.

AB: But there are traditional laws to uphold.

Tony: But not in a court of law.

AB: We are yet to approach a member of the community who has been the recipient of all of this important and healthy research. Rowena, you must hold the Guinness Book of Records all-time record for involvement in research. Can you take us through some of the research you have been involved in?

Rowena: Well the first was in 1954. I was asked to be involved in some heart study. It seems that they were starting to think that smoking was bad for you. I was always told that it was OK. You know my doctor used to smoke in his office, and in the hospital. I mean what if one of his patients was on oxygen? I never understood why one of them didn't blow up.

AB: What were some of the other studies you have been involved in?

Rowena: Well then there was the lead study of the 60s, the bowel cancer one in the late 60s, the diabetes and heart disease study in the 80s, the breast cancer and halothane study of the 90s, the melanoma, stroke, blood pressure and cholesterol study of the late 90s.

AB: How did all this research make you feel?

Rowena: Well I've been explored, probed, lost more blood than a haemophiliac, fasted, measured, poked, ran on a treadmill for 5 hours, breathed into some machine that looked like my fridge. I have sample from every bit of me taken; sputum, saliva, urine, bits of my stomach chopped out by a big black snake that they shoved down my throat, faeces, blood, and cervical cells.

I have even had my breasts squashed between two big cold plates. The last study they told me I had a high beta-carotene level. You know what was strange? I don't even like carrots.

AB: Well after being involved in so many studies, you must be one of the healthiest people around.

Rowena: Not at all. After a while you don't feel like a person anymore. I felt like I had given my body to science, but I was still alive. I thought I was healthy until they kept telling me I was sick with all this stuff I had never heard of. If anything all this study has made me sick.

AB: Well after a lag time of a few weeks, the submissions begin to come in thick and fast.

NACCHO seem convinced that they will get some money to develop guidelines into research protocol for Indigenous communities. Maria and associates developed a submission to address community priorities in research and to validate Indigenous concepts and culture as a methodology of research. The Ungrateful Native Department of the University of Adelaide develops something to look at political radicalism of Indigenous Australians and unemployment (something to do with the fact that it's all their fault).

The submission by Tony Barnes was basically to assess the value and needs of Indigenous health research into the next 20 years, subsequently asking for all of the 15 million dollars so as to set up a National Institute of Indigenous Research. Unfortunately he failed to consult any community member. He decided that the involvement of Mark was enough to adequately address Indigenous concerns.

This submission was fast tracked by Kerin and passed on to Treasury and the PM. The PM agrees with the 'vision', despite the cries of inequity of the National Party and One Nation. Basically the proposal was successful, with all of the money going to the one consortium.

A media launch of the newly established NIIH is planned within three months on the lawns of Parliament House (just next to the Aboriginal Tent Embassy). Unfortunately the local Aborigines won't support it. In an effort to have some Aboriginal faces involved in the launch, Tony agrees to fund the transportation of 80 low security prisoners from Kingaroy Queensland who are forced to welcome and congratulate the Government and the Institute.

The 'Institute', as it is known, begins in a blaze of glory with a study into Indigenous IQs and mortality. The Institute is run by Tony Barnes and his good friend Kerin O'Dea.

Meanwhile Maria and associates continue to struggle for funding. All submissions have to go through the Institute, which holds a grudge and won't part with any cash.

Mark remains an important cog in the empire of the Institute, despite the fact that very few people will listen to him. He eventually quits the organisation and becomes a youth worker at the Gap Youth Centre in Alice Springs.

Daniel becomes a lecturer in the Ungrateful Native Department at Adelaide University but soon is fired when he raises the ideas of cultural equivalence and listening to communities.

Rowena settles back to her life in Double Bay, waiting for the next random digit-dialling questionnaire. It transpires that she is enlisted for a study into a new analogue dual action cholesterol and free radical control drug. Unfortunately, she develops severe complications, and is the first fatality because of the drug.

Glaxo is taken to court and ordered to pay 100 million dollars in compensation to the estate. As part of the will, Rowena has bequeathed all of her money to help Indigenous research in Australia.

Tony Barnes watches the news report with obvious interest. The dollar signs start spinning again.

And the moral to the story is.....





APPENDIX C

Yarning workshop participant list

Dan McCaullay

Geoffrey Angeles

Mai Katona

Norma Bengier

Jason Davidson

Terry Dunbar

Yin Paradies

Brendan Loizou

Alex Brown

Mark Mayo

Lorna Murikami-Gold

Christine Franks

Joanne Garngulkpuy

Lawurra

Sarah Walton

Betty Marrnganyim

Loyla Leysley

Isaac Brown

Veronica Arbon

Leah Ahmat

Shelley Ahmat

Louise Ragg

Sally Matthews

Maria Scarlett

Joan Cunningham

Christine Connors

Anne Lowell

Allan Arnott

Rowena Ivers

Jeannie Devitt

Michelle Dowden

Anthea Duquemin

Michael Christie

Bart Currie

Robyn Williams

John Grundy

Ely White

Kerin O'Dea

Tony Barnes

Amanda Leach

Jenny Brands

Peg Carmody

Sandy Ball

Sallie Hudson



