Australian Government

National Health and
Medical Research Council

NHMRC

NHMRC accredited
Centre for Innovation
in Regional Health

Researcherenye
Wappayalawangka

Central Australia
Academic Health Science Network

NHMRC AHRTC and CIRH Reporting

Better Care

What health services (e.g., procedures, preventative measures, treatments or devices) has the centre developed, tested, implemented and scaled-up, or eliminated, to deliver better care for patients?

HTLV-1 Mother to Child Transmission Study

Project Lead: Lloyd Einsiedel (Baker)

Strategy to address this issue and progress to date

- Recruiting specialised project staff: In order to conduct this study in a way which is both culturally and gender sensitive, it was important our study team included mature local Aboriginal women who would be able to approach sensitive discussions with potential participants.
- Promoting awareness about the study: It was important to ensure assistance from relevant health care providers in promoting the study to potential participants. Therefore, at commencement of the study, we spent significant time discussing study objectives with health care staff at ASH Paediatrics and Maternity Units, Alukura Women's Clinic and Congress-run community clinics within the study area.
- Recruiting women to the study: Interested women who fit the inclusion criteria met with members of our study team when they visit antenatal clinics are either the Hospital or Alukura.

What measures/metrics (a maximum of five) you will use to determine if you have succeeded

1. Determine whether the proportion of Aboriginal women in our study area who consent to enrolment in a pilot study of MTC transmission will be sufficient to render a large-scale study feasible.
2. Understand if the collection of clinical material (dried blood spot, breast milk and cord blood) from infants is acceptable to Aboriginal women and their families
3. Understand if the follow-up of Aboriginal mothers and their infants is feasible in our setting
4. To determine if HTLV-1 proviral load can be accurately quantified in breast milk and dried

blood spots taken from infants

5. Collect information from women and their families relating to infant feeding, which will be used to develop an 'Introduction to Solids' program appropriate to Aboriginal families in central Australia.

Impact pathway.

Project has refined models of recruitment of women, with family support, in recruiting to the study

Findings now being folded into major HTLV-1 longitudinal study supported by a Department of Health grant $4.5 million)

HTLV-1 Mother to Child Transmission Study

Challenge/problem

The HTLV-1 Mother to Child Transmission Study is a study designed to determine whether current National Infant Feeding guidelines are acceptable to Indigenous women and whether their implementation could safely improve infant nutrition while reducing HTLV-1 transmission to Indigenous children in central Australia.

Approach/response

- Recruiting specialised project staff: In order to conduct this study in a way which is both culturally and gender sensitive, it was important our study team included mature local Aboriginal women who would be able to approach sensitive discussions with potential participants. Baker successfully recruited a female Aboriginal Research Officer to join the Baker team, and we were also joined by a female Aboriginal Research Officer from Congress (support provided in-kind) to work on the study.
- Promoting awareness about the study: It was important to ensure assistance from relevant health care providers in promoting the study to potential participants. Therefore, at commencement of the study, we spent significant time discussing study objectives with health care staff at ASH Paediatrics and Maternity Units, Alukura Women's Clinic and Congress-run community clinics within the study area.
- Recruiting women to the study: Interested women who fit the inclusion criteria met with members of our study team when they visit antenatal clinics are either the Hospital or Alukura. Potential participants were also been approached if they were admitted to the Hospital maternity ward for any reason. During this initial contact, the study team discussed the study in detail, in primary language when possible, to ensure women had full understanding of the study, what participating in the study would mean for them, and their right to withdraw their participation at any time.
- We have gained valuable insights into barriers and incentives to recruitment in this context, and logistics of obtaining specimens in an antenatal setting. Although we were not able to recruit all 115 women we approached in the study, we were able to build an understanding of why people did not want to participate, and other valuable information which will influence the next stages of our study:
- Women overwhelmingly recognised the need for research into reducing risk of MTC HTLV-1 transmission, but recommended that i)recruitment be done when women attend
- The number of people who do not consent also included those who were approached by health staff (prior to meeting with the team) when this information was made available to us. clinics for antenatal care in their home communities, and ii) that their male partners and other family members receive education about the project and are involved in the consent process.
- Interviewees expressed no concern about the collection of biological samples including maternal blood and breast milk, cord blood or infant blood by skin prick. This finding was consistent with advice received from a local Aboriginal Women's Advisory group. We therefore decided to proceed with an intervention study to implement national infant feeding guidelines, which recommend the introduction of solids at 6 months, using a single arm trial design, and have submitted an NHMRC application with our study partners.

Significance

The project has proved an vital guide to expanding the study of the prevalence of HTLV-1 into Western Australia working with the Ngaanyatjarra Health Service prior to an expanded, culturally appropriate, recruitment process. This knowledge will be incorporated in what will potentially be a ten-year longitudinal study funded by the Department of Health (yet to be publicly announced by the Department). Aboriginal governance of the will be carried out under the auspices of the Central Australia Academic Health Science Network

Reach

Building on findings and experience gained in this feasibility study, Baker and its collaborating partners have developed and submitted research proposals to extend our research on the HTLV-1 MTC study to the next stage of work. This has included applications to NHMRC and philanthropic organisations. The Central Australia Academic Health Science Network [CA AHSN] has allocated MRFF-approved funding to extend Baker's Longitudinal Study on HTLV-1 over two years into Ngaanyatjarra lands in conjunction with the Ngaanyatjarra Health Service. Learnings from the HTLV-1 Mother to Child Transmission Study will be incorporated into this work.

Meeting Catchment Needs

How is the centre meeting the needs of its population, including vulnerable groups?

Aremele Arratye Mpwaretyeke – Doing It Right: Research Knowledge Generation and Translation in Central Australia

Project leads: Bronwyn Silver (CAAC) and Leisa McCarthy (Menzies)

While general "health research literacy" in the Australian public in general is low, issues such as low knowledge of English language; a history of "top down" research; exacerbate low health research literacy among Aboriginal communities.

This project will assist Aboriginal community members, the health service and Board members to improve their understanding of health research processes, benefits and outcomes and be empowered to become an equitable partner and drive the research agenda.

Strategy to address this issue and progress to date

In the process of development of a range of tools to assist ACCHS Boards, Research Subcommittees and the Congress Research Unit to assess, monitor and record knowledge generation and translation. These will include but are not limited to guidelines, assessment criteria, audit tool and a recording, monitoring and evaluation system.

Measures/metrics to determine if you have succeeded

1. The number of ACCHs' Boards that participate in/adopt *Aremele Arratye Mpwaretyeke – Doing It Right*
2. Finalising tools
3. Published results for translation

Where on impact pathway

Expanding *Aremele Arratye Mpwaretyeke – Doing It Right* to five communities ACCHs

Aremele Arratye Mpwaretyeke – Doing It Right: Research Knowledge Generation and Translation in Central Australia

Challenge/problem

Health research agendas have mostly been imposed on Aboriginal people in Central Australia with little or no meaningful exchange of knowledge and understanding. Though there has been some improvement, meaningful engagement and commitment to knowledge translation remains ad hoc and disjointed. This project will assist Aboriginal community members, the health service and Board members to improve their understanding of health research processes, benefits and outcomes and be empowered to become an equitable partner and drive the research agenda.

Approach/response

1. Literature review and investigation of Aboriginal community engagement in research
2. Using a ‘both ways’ approach to generate research knowledge between Aboriginal community members and health researchers. This includes:
    a) Local radio talk back show on research in Central Australia.
    b) ‘Research Roadshow’ or community forum held in Alice Springs and 5 remote Aboriginal communities.
    c) Translation of NHMRCs ‘Keeping Research on Track’ into local language. Innovative and creative formats will be investigated, such as animated videos.
    d) Development of a ‘Working Together’ guideline that outlines ACCHS expectations of research partners when conducting research.
    e) Using an integrated quality improvement framework, an audit of all ACCHS approved research projects will be undertaken.
    f) Identification of missed opportunities for knowledge translation for policy, practice and health service delivery.
    g) Development of three case studies on a range of current research projects nearing completion using an integrated quality improvement framework.

Significance

Aremele Arratye Mpwaretyeke – Doing It Right is not to be seen as an end in itself, but as an iterative process that can be expanded and developed over time as the research content and control changes and develops. The anticipated building of capacity to initiate, understand and participate in research at the community level is critical, from the instigation to translation. It will:

- Generate research knowledge by and for Aboriginal community and health service Boards
- Empower community members in understanding research and its benefit
- Implement knowledge translational activities that can improve service delivery
- Provide employment and leadership opportunities for Aboriginal Researchers
- Support ACCHS Boards by providing guidelines to assess, record and monitor knowledge translation activities
- Achieve best practice in meaningful partnered research that will benefit Aboriginal Community Controlled Organisations and their clients and be shared with other ACCHS

Reach

In step with other CA AHSN initiatives (see answers to Questions 4, 5 and 7 below) the development of a blueprint from the action/ research process of *Aremele Arratye Mpwaretyeke – Doing It Right* can potentially be adapted/translated to other areas of remote Australia.

End User Involvement

Part A: Short answer (maximum ½ page)

Changing the Landscape of Health Research

The conventional model of health research—that of “top down” research initiated by scientists—is particularly fraught in engaging vulnerable groups. This is particularly the case in remote regions with high Aboriginal populations who face very poor health outcomes compared to the general population.

To date, research agendas have mostly been imposed on Aboriginal people in central Australia with little or no meaningful exchange of knowledge and understanding. Indeed, a significant number of Aboriginal health organisations have declared moratoria on involvement in *any* externally designed health research due to overwhelming “pressure” from researchers.

The primary focus for CA AHSN to “change the landscape” has been to emphasise and increasing the level of direct involvement by Aboriginal health organisations—all of which are controlled by their members as “consumers”—in the research process.

In the latest round we have pushed this out to requiring *all* projects to be community [consumer] initiated, developed by our community members in partnership with institutional members.

Measures/metrics:

1. The direct involvement by community partners in research as participants and/or research leaders
2. The number of community partners that develop and/or enhance in-house research committees
3. The number of community partners that lift moratoria on research
4. The extent to which we can identify increased “research literacy” amongst community partners

Impact thus far:

Thus far, two of our community partners have lifted research moratoria; a new research sub-committee has been established by one of our community members.

Changing the Landscape of Health Research Community Round Table

The challenge

Empowering community members of CA AHSN to initiate, design and lead health research.

Approach/response

Initially, MRFF research proposals were *required* to partner with CA AHSN community members [half our membership] in initiating and developing research projects.

Responding to the CA AHSN Council's decision that the next round of MRFF funding be refocussed in this manner, a Call Out to all our community partners to examine the health research priorities they have, and bring research concerns/proposals to what was named the *Changing the Landscape of Health Research Community Round Table*, which was held over two days in February.

The central theme of the Round Table was stated by CA AHSN Chair, John Paterson: "What we are trying to do is take the next steps forward in changing that landscape; and taking ownership of that landscape. And this is something that CA AHSN has been working towards from the beginning."

The Round Table comprised presentations of ideas, from which key themes and research questions were developed. Notably, there was strong attendance and support from senior members of our managing partners in the universities and research institutes; in government and other representative organisations.

Significance

The Round Table resulted in nine research proposals from our community members in partnership with our institutional members.

Specifically built into the process has been ongoing financial and expert support to our community partners to develop and lead research projects. This support has been in the form of one-off grants to employ expertise as well as ongoing support by a CA AHSN staff member dedicated to this process.

Capacity building is at the core of this process, both organisationally and in the work of Aboriginal and Torres Strait Islander researchers that will hopefully be involved in leading roles. As far as we are aware, nothing like this has ever been attempted in Australia before—certainly on this scale.

The resulting research proposals were diverse, and included research around health workforce, social media and cyberbullying; factors affecting chid health in remote Aboriginal communities; nutrition and food security research and program; primary health care and avoidable hospitalisation; and renal research knowledge translation.

Reach

Seven of our community partners will lead research projects—from two project leaders in the first round of MRFF funding. As part of ongoing evaluation of the projects, and the ways they might inform and intersect other MRFF-funded projects being undertaken by CA AHSN, we anticipate the learnings of the *Changing the Landscape of Health Research* process to inform similar initiatives elsewhere in Australia.

Workforce

How is the centre building workforce capacity and capabilities in research and translation to ensure health professionals have access to evidence-based education and training and are contributing to health research?

A primary objective of the CA AHSN is:

- Workforce and capacity building, with a strong emphasis building the Aboriginal and Torres Strait Islander research community

Our informal aim is to double Aboriginal and Torres Strait Islander employment in central Australia in research by 2024

Strategy to address this issue and progress to date

1. Funding of 15 Cert II course (through Menzies) for Aboriginal and Torres Strait Islander researchers
2. Support to Tangentyere Council in obtaining accreditation training for researchers using First Nation Languages
3. Funding of 10 people in Praxis ethic training, an accredited course. *Inter alia*, this will qualify people to be able to serve on HRECs
4. Development of First Nation Languages in Health Research Protocol, with an emphasis on accreditation of interpreters/translators in research
5. Establishment of Aboriginal and Torres Strait Islander researchers local network
6. Maximise employment for Aboriginal and Torres Strait Islander researchers, at all levels, in CA AHSN projects

Measures/metrics to determine if you have succeeded

1. Graduation rates at all levels of research for Aboriginal and Torres Strait Islander researchers
2. Employment levels for Aboriginal and Torres Strait Islander researchers
3. "Exit surveys" of Aboriginal and Torres Strait Islander researchers as projects are completed
4. Adoption locally, and potentially nationally of the First Nation Languages in Health Research Protocol

Where on the impact pathway.

Early days yet, but we are finalising a survey of local Aboriginal and Torres Strait Islander researchers to determine their needs.

A sub-committee has been established to develop the First Nation Languages in Health Research Protocol

Have established a "Quick Response" funding scheme for discrete short term research efforts and/or assistance with publications/presentations.

Partner Contribution

How are the partners of the centre contributing to its operation?

Financial

Five of our institutional partners contribute $30,000 each per annum; while one of our community partners—as administering partner—contributes $30,000 in kind.

Further in-kind/ Operational

As well as in-kind support to individual projects (which adds approximately 50% to the value of the projects), partners have made available staff time and expertise in support of the CA AHSN's operations. In addition, support has been extended in support of AHRA NSLIs and special interest Networks.

Governance

All partners provide support to our operations through our governance structure. Contributing partners attend fortnightly Management Committee meetings; all partners contribute through attendance at Council meetings through the year. Notably—and as a matter of informal policy—partners most often have at least two staff members attend all meetings, at no small cost in time and effort.

Strategic support

Partners are increasingly involved in contributing to our operations including, but not limited to: Policy development (such as the First Nation Languages in Health Research Protocol noted below at Question 7); the development of Evaluation frameworks for the Network; along with the development of Strategic planning tools.

Clinical Trials

Have you improved processes (e.g. ethics and/or governance arrangements) so that your patients can access clinical trials more easily and/or sooner?

Short answer (maximum ½ page)

The CA AHSN is not presently involved in Clinical Trials.

However, in anticipation of potential future involvement in Clinical Trials—and indeed as a central tenet of our research practice in ethical and governance terms, we are currently developing a First Nation Languages in Health Research Protocol. In this, we will be partnering with the Lowitja Institute and SAHMRI.

First Nation languages are part of daily life throughout central Australia—as a point of cultural strength and knowledge, as well as a point of difference within the colonial structures that still prevail. Many Aboriginal people in the region speak English as a second, third or fourth language—if English is spoken at all. Very, very few non-Aboriginal people in the region are conversant in a First Nation Language.

The effects of this are obvious. While the poor English language and literacy might be regarded as one of the social determinants of ill health this is, arguably, part of the deficit discourse, ignoring the positive health benefits of language and, hence, cultural knowledge and authority. Many First Nation languages are critically endangered so privileging them in research projects has a double health benefit.

Use of First Nation languages in health delivery has been identified many times by the CA AHSN partners over many years, not least the recent and continuing work of NPY Women's Council in its Ngankaṟi and Uti Kulintjaku initiatives, and within our MRFF-funded research projects.

All CA AHSN partners are committed to expanding Aboriginal direction and control of health research efforts and a First Nation languages policy will contribute significantly to those efforts. However, there is no formal policy or protocol regarding First Nation languages within health research in Australia. More than half of the 20 research projects on CA AHSN's books will involve the use of interpreters and translators and the production of audio and visual material in one or more of the region (or continent's) First Nation's languages.

Use of First Nation languages to be an important consideration by Human Research Ethics Committees

A First Nation's language policy or protocol to assist in health research is essential in this, the International Year of Indigenous Languages. A very quick check with Lowitja and SAHMRI suggests that there is no such policy document in existence, and that they would welcome partnering in its development. When adopted, we anticipate the policy/protocol would be distributed nationally, not least to the MRFF, NHMRC and AHRA.

It is likely the Protocol may inform broader research processes involving Aboriginal and Torres Strait Islander peoples (social/environmental research). It might conceivably inform research involving people of NESBs.