

Supplementary Material

Community-driven health research in the Torres Strait

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Community-driven health research in the Torres Strait: supplementary material

Examples of initial ‘one-pager’ research proposals in various stages of development

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### One-pager: initial research proposal (1)

Name[s]: AA

Version 3, May 27th 2019

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#### 1. Background

- Many households in my community and other communities do not have a reliable water supply
- This causes unnecessary distress for families in these households. Access to fresh water is a human right. Lack of fresh water poses a health risk.
- The problem is chronic and seemingly insoluble. Numerous excuses have been offered by the relevant authorities as to why water supply is so regularly interrupted. No progress has been made despite repeated requests from families across the community.
- A study to identify the logistic [plant and equipment], bureaucratic and financial blocks to progress on this issue would likely strengthen the case for action on behalf of the relevant authorities.
- Some survey work around housing issues has already been done with 34 households on Darnley Island

#### 2. The research question

What stands in the way of an acceptable community water supply?

#### 3. Methods: how we approach the question

This will be a prospective mixed-methods study consisting of a household survey plus a brief interview with willing householders, local water engineers and water authority administrators.

A one-page straight-language survey tool will be developed and trialled.

The researcher and assistants will then visit each of the 34 participating households on Darnley Island to conduct the survey. The head of each household will also be specifically asked the study’s research question. They can write the answer down or answer verbally, to be recorded on a mobile phone. The researcher has identified key people in the community and TSIRC, especially local people responsible for the water supply. They will be interviewed and asked the same research question. The survey tool will also be used in other nearby island communities if the opportunity arises.

The survey results will be de-identified and entered onto an Excel database for analysis. The answers to ‘the question’ will also be de-identified, transcribed [where necessary], collated and analysed using qualitative analysis methods [with the assistance of expertise from JCU].

#### 4. Resources needed and available

The main resource will be time. This study will be quite time consuming. But it won't require much else in the way of resources, apart from some expertise in analysis.

## **5. Potential outcomes**

- The conduct of this study is likely to have positive consequences, even before it is finished. If completed and published, it would shine a light on the 'roadblocks' and go a long way to providing solutions for this community and others in the region.
- This would be a powerful demonstration of a community-driven research project that has important practical health consequences for the community, and wider population.

# **One-pager: initial research proposal (2)**

Name[s]: **BB**

Version 2, 22<sup>nd</sup> February 2019

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## **1. Background**

People requiring palliative care are far better off being looked after in their own communities

There are currently limited palliative care services in many Torres Strait communities

Research evidence is required in order to put up a case for finances and resources to establish and run better palliative care services that are community-based

Families of people who have received palliative care services can provide the best information regarding the value of in-community palliative care

## **2. The research question**

How does the community value palliative care?

## **3. Methods: how we approach the question**

Participants: family members of people who have received community palliative care in the last 2 years [estimated at 30-40 people in community]

Informed consent: including explanation of the study and the reason behind it; potential participants can say 'no'; participants' privacy will be protected

Research will use a mixed methods design

Quantitative survey: development of a brief [one-page] survey tool; researcher goes through the survey with each participant. Survey entered into Excel for analysis

Qualitative arm: family members asked to briefly tell their story about the palliative care, each story recorded, transcribed and analysed in nVIVO

## **4. Resources needed and available**

Study protocol planning and survey design: support can be provided by Luisa and Malcolm

Informed consent documents and ethics application: guided by Luisa

Mobile phones used to record stories. We can try using a transcribing app. [if not, we'll need someone to do it]

Data analysis: in collaboration with Luisa, Malcolm and others experienced in qualitative analysis

## **5. Possible outcome[s] and impact[s]**

A publication demonstrating how much family members value community-based palliative care will encourage establishment of services in the author's community and communities across the region

A publication about community-based palliative care will highlight the overall importance of this approach

# **One-pager: initial research proposal (3)**

Name[s]: CC

Version 2, 1<sup>st</sup> April 2019

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## **1. Background**

Torres Strait Islanders and Aboriginal Australians often have high health needs. Common adult conditions [in > 50yr-olds] include diabetes mellitus, cardiovascular disease, respiratory disease, kidney disease, dementia and mental illness

The provision of services in the Torres Strait faces many obstacles; these include remoteness, difficulty with communications, limited community infrastructure and professional skills, expense and bureaucratic delays

Following assessment by Regional Assessment Service (RAS) team and/or Aged Care Assessment Team (ACAT) there are often long delays before critical services are provided. Serious hardship and adverse events can and do occur during this waiting period. Documentation of the delays and the cost of delays for patients and their families will strengthen the case for more timely service provision for this vulnerable group of people.

## **2. The research question**

What are the consequences when services are delayed after ACAT/RAS assessment?

## **3. Methods: how we approach the question**

This will be a prospective cohort study in collaboration with the local ACAT/RAS teams

It will involve 25 people consecutively assessed by the local ACAT/RAS team

Once assessment has been completed: informed consent will be gained from patients/carers/families

Each enrolled patient/carer/family will then be contacted weekly by phone/home visit until services are in place. The study will record time to service provision and any reported hardships/adverse events during the waiting period on an 'incident form'

Information will be de-identified and entered onto an Excel database for analysis. Results of the study will be returned patients and families.

## **4. Resources needed and available**

- The study will require the co-operation of the local ACAT/RAS teams.

- It would also be helpful to have some expertise available to assess the financial cost of delays: including unscheduled clinic attendances, hospitalisations, etc

## **5. Possible outcome[s] and impact[s]**

Should this study demonstrate high health and financial costs of delayed service provision, it would greatly strengthen the case for increased resources to ensure more timely action following ACAT/RAS assessment.