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Community-driven health research in the Torres Strait

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[#]The Australian Institute of Tropical Health and Medicine (AITHM) Torres Strait Community-Driven Research Collaboration: The late Romina Fujii (founder), Lynda Ah Mat, Malcolm Brown, Jennifer Calixto, Stephen Christian, Debra Claire, Cadhla Firth, Sue Forbes, J'Belle Foster, Tanya Govey, Allison Hempenstall, Alex Hofer, Jaqui Hughes, John Jackey, Sam Jones, Ella Kris, Shirley Kusu, Louise Manas, Collin Messa, Sam Mills, Laura Morseu, Phillemon Mosby, Michael Muhamad, Patty Nakata, Pelista Pilot, Luisa Roeder, Sean Taylor, Alice Thomas, Hylda Wapau, Felecia Watkin-Lui (facilitator), Aiaga Whap and Allison Wolf. Hot North was both participant and major funding body.

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ABSTRACT

Background. In July 2018, participants at a Waiben (Thursday Island) conference declared that it was time for a locally driven research agenda for the Torres Strait and Queensland Northern Peninsula Area. For decades, they felt exploited by outside researchers. They identified a lack of respect and consultation, with few benefits for their people. **Methods.** In response, the Australian Institute of Tropical Health and Medicine (Waiben Campus-Ngulaigau Mudh) invited a consultative group of elders and senior health providers to develop a research program based on local cultural and health needs. The aim was to promote research skills through a learn-by-doing approach. Four workshops were conducted over 2019. Key financial and in-kind support was provided by the Australian Institute of Tropical Health and Medicine, Hot North, and Queensland Health's Torres and Cape Hospital and Health Service. **Results.** The first workshop attracted 24 people; none had previous research experience. The workshop format evolved over 2019, mainly guided by the participants. Overall, feedback was positive, and participant research proposals remain in various stages of development. **Conclusions.** Although suspended during the COVID-19 pandemic, this is a long-term investment in community-driven research that seeks to translate health benefits to the people. This model may apply to other communities, especially in rural and remote Australia.

Warning: This article contains the names and/or images of deceased Aboriginal and Torres Strait Islander peoples.

Keywords: capacity-strengthening, community driven, Indigenous research, primary health-care, Torres Strait, workshop.

Introduction

The Torres Strait covers 48 000 km^2 of ocean between Cape York and Papua New Guinea; 2.6% of this area is land (Torres Strait Island Regional Council (TSIRC) 2016). The population of the Torres Strait plus the Northern Peninsula Area (NPA) is just over 7000 people (Australian Bureau of Statistics 2016). It is culturally and linguistically diverse with social systems based on traditional, family, and community obligation. The relatively poor health of the population, when compared to the rest of Australia, remains of longstanding concern (Australian Bureau of Statistics 2019). Yet, many people of the Torres Strait feel that they are some of the most over-researched people on the planet, with little benefit to show for it.

The Torres Strait Community-Driven Research Initiative began at the Hot North Conference on Waiben in July 2018 (Hot North 2018). Hot North is a multidisciplinary and collaborative research organisation across Northern Australia. It comprises eight health research bodies, including the Australian Institute for Tropical Health and Medicine (AITHM), based at James Cook University (JCU). At the 2018 conference, local participants stressed that it was time for a community-driven Torres Strait and NPA research program. Several senior community members expressed dismay. They claimed that 'research has become a dirty word here.' They felt ogled, exploited, and

burdened by outside researchers over decades. They pointed to a lack of respect and consultation that accompanied many mainland-based research projects. They also felt there had been few, if any, lasting benefits for their people. The tension in the hall was palpable.

Key local health professionals agreed with the leaders' concerns and insisted that it was time for local people to acquire the skills sufficient to drive a Torres Strait research agenda. In addition to potential health benefits, such an initiative would foster regional education and training with related employment opportunities. A similar message was expressed by participants of a JCU-AITHM afternoon workshop in November 2018 at the official opening of the new Waiben AITHM building. Participants wanted to develop a local nucleus of proficient researchers, people best placed to identify and address the key health issues of the region. The prime mover of the new initiative was the late Aunty Romina Fujii, Chair of the JCU Torres Strait Health Sciences Research Subcommittee and longtime champion of locally based research.

Methods

The AITHM response was to propose a Torres Strait-based community-driven and community-owned research development program. AITHM sent out an expression of interest email to local councils and health services across the Torres Strait and Cape York. In January 2019, a Torres Consultative Group was established, primarily of community elders and senior Torres Strait Islander healthcare providers. The group proposed a program based on an initial series of four 2-day workshops over 2019 (Box 1). Workshop activities would be conducted around a Torres Strait cultural framework. The Torres Consultative Group was led by Aunty Romina Fujii. She stressed the need to focus on local health issues, fostering research skills through a learning-by-doing approach rather than by 'top-down didactic teaching'.

The free-of-charge workshops were conducted at Ngulaigau Mudh (the Waiben AITHM Campus) in 2019. Participants from communities outside Waiben were provided with transport and accommodation by AITHM with the financial and in-kind support of Hot North and Queensland Health's Torres and Cape Hospital and Health Service. All participants were given study leave by their employers to attend.

Once the background and proposed process were explained at the first workshop, participants were asked to sign a consent form, noting that their name and photograph could be used in later published reports of the program. Although the program broadly kept to the basic format, each workshop was loosely structured and informal. Participants first formed four small multidisciplinary working groups. They focused on identifying issues that mattered to local people, ensuring every participant had a say and with plenty of time for free discussion. A key aspect was flexibility; activities could

Box 1. The workshop curriculum

Workshop 1: Asking the right questions

- The local Torres Strait perception of research. Why is this so? What can be done?
- What is research? Why do research?
- Types of research: basic, clinical, populations, databases
- What is community-driven research?
- Approaches to asking questions that matter. Can the questions be answered?
- Has this question been asked before? What is known already? Searching for available information
- Helping workshop participants to frame their own questions

Workshop 2: Ways to address the questions in an ethical and cultural context

- Qualitative and quantitative research. Mixed methods
- Different types of research study design and why we would choose them
- Assessing available resources [including time] to answer the question. Who is involved?
- Creating a research protocol: the question, the methods [within a cultural framework], the timeframe and budget
- Ethics approval
- Applying for funding
- Participants will create one-page research protocols to address their questions

Workshop 3: Collecting and handling the information

- What to measure? Research endpoints and why they matter
- Privacy issues
- Setting up a data collection tool
- Setting up a database
- Data cleaning and crunching
- Ways to report the findings
- Potential hurdles and obstructions
- Participants will process and present any data collected to this point

Workshop 4: What to do with the results

- Feedback to individuals, families, the community, contributors and funders
- Targeted feedback: policy-makers
- Conferences and other meetings
- Internal reports
- Writing a paper: participants will write one or more brief 'publishable' reports together
- Explore ways to translate the findings into community health benefits; focus on sustainability
- Setting up a long-term research agenda with sustainable ways to cultivate local research capacity

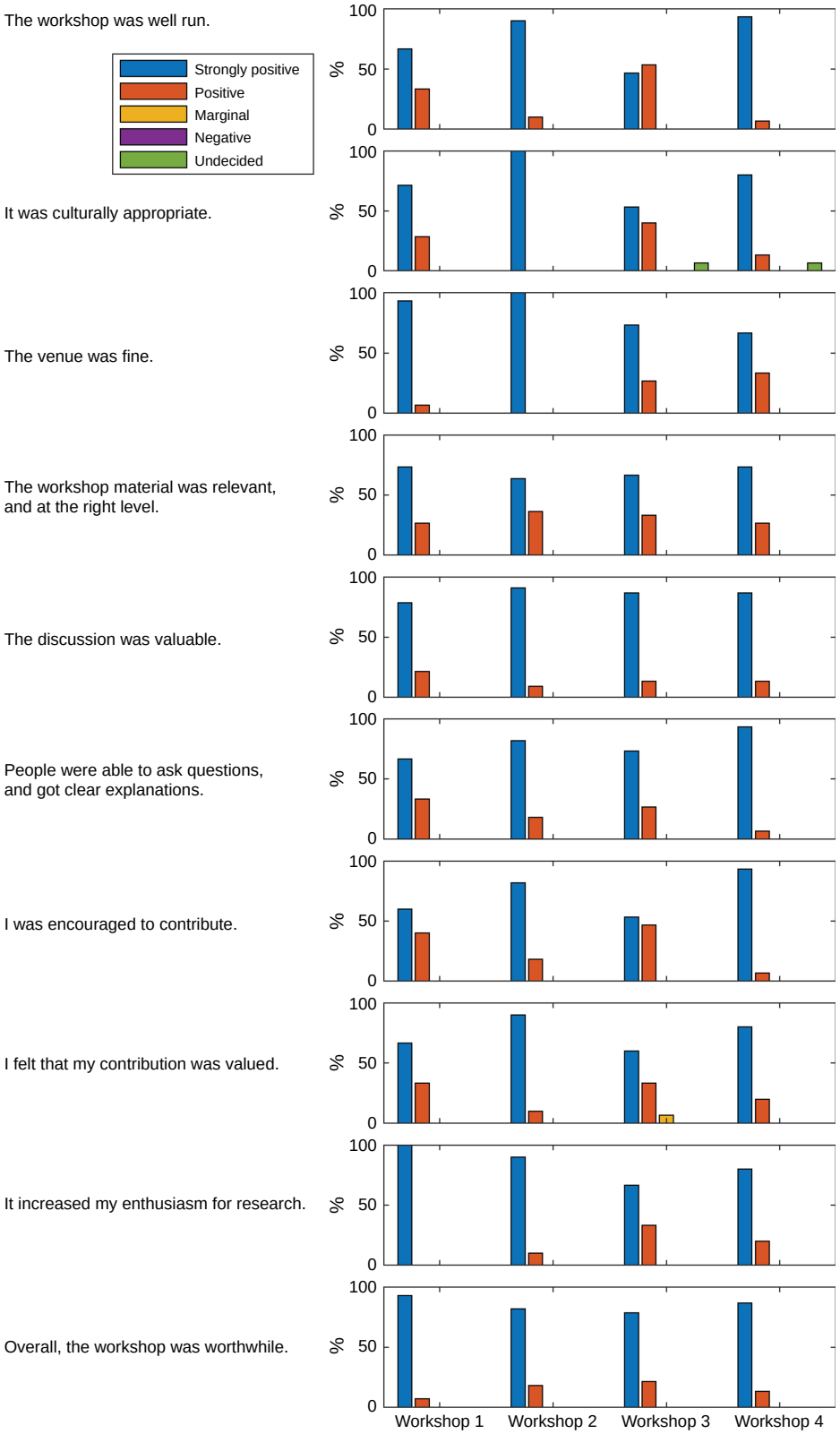

Fig. 1. Combined feedback from the four Waiben workshops.

change course or emphasis as required and at any point. Real-time participant feedback was direct or through the Torres Consultative Group. Feedback determined the pace and workshop direction at each phase. Participants also provided written feedback in the form of a questionnaire at the end of each workshop (Fig. 1). These data were collected to evaluate

acceptance of the program. The North Queensland Health Human Research and Ethics Committee (HREC) had approved collection and use of these data prior to the first workshop (LNR/2019/QCH/52013(Feb ver1)–1326 QA).

The direction of the workshops loosely followed the stages of a typical research project life cycle (Box 1): developing research questions, undertaking systematic literature searches, study design and research methodologies, writing study protocols, preparing research ethics applications, collecting and analysing data, presenting, and publishing. The first task was to determine the current perception of Torres Strait research history from workshop participants. Participants were asked 'why is this so?' and 'what can be done?'. Responses from each of the four groups were recorded and collated.

At each subsequent workshop session, the groups rearranged themselves, and facilitators started the day by presenting research concepts in a stepwise manner. This was followed by interactive activities and discussion. As the program progressed, participants proposed and developed their research questions; some worked alone, and others in collaboration. The initial aim was to produce one-page proposals that were then presented to the larger group for discussion and constructive input. If judged to be appropriate and feasible, participants revised and expanded their 'one-pager' accordingly. A small number of initial proposals were abandoned due to feasibility issues or the scope of the proposed project and replaced by new ones.

Facilitators provided online support between workshops for participants as they developed their ideas. They also posted all workshop materials, tutorials, relevant publications and presentations, research proposals, ethics forms and related documents online through Microsoft Teams. Participants, guests and facilitators had password-protected access. Each workshop had invited guest mentors. These included prominent Torres Strait Islander researchers from research centres outside the Torres Strait. They came from Far North Queensland, the Northern Territory, and Western Australia. The Chair of the Far North Queensland Human Research and Ethics Committee attended the last workshop.

The program was suspended in January 2020 due to the COVID-19 pandemic and related travel restrictions. Torres Strait researchers and JCU began the process of re-establishing activities in early 2021. The program's future now depends on sustainable funding and local resources.

Results

AITHM received 24 expressions of interest from community members across the Torres Strait and Cape York, three times the expected and originally budgeted number. After deliberation by senior AITHM administrators, every applicant was accepted into the program. The participants represented people from various backgrounds, including community welfare officers, Indigenous health workers, nurses, allied health practitioners, health trainees and medical officers. Over half the participants were Aboriginal and/or Torres Strait Islander Peoples. The remaining participants were non-Indigenous people living and working full-time in the Torres Strait and Cape York communities. Over the 2019 workshop year, four people left the program, all for unexpected work commitments, and six people joined. If participants were unable to attend a workshop, they could nominate a colleague who would attend in their place. Two of the replacement nominees were additionally enrolled for the remainder of the program.

On the morning of the first workshop, participant groups were tasked to address three questions:

1. What is the local perception of research?
2. Why is this so?
3. What can be done?

There were insufficient data from the five group summaries to conduct formal thematic analysis, but several common viewpoints emerged. One Torres Strait Islander community worker noted that 'there were two groups of people in the room, one group shared from a clinical health perspective, and the other shared from a grassroot level'. For the first question, local participants felt that most previous research projects in the Torres Strait were 'outside intrusions' that had little community ownership and were controlled from afar. They lacked a cultural framework, often had a negative focus ('they measured problems'), and provided no lasting benefit to the community. Answers for the second question included: lack of cultural respect, insufficient consultation, fear of communities being shamed, discrepancies in perceived health priorities, and geographical remoteness. Responses to the third question were: the need to frame research in a cultural context, community consultation in local language, determining community health priorities before starting any project, addressing locally determined health issues, training of local researchers, and demonstrating community benefits of research.

Workshop participants came from different backgrounds. But once people started the small group process, there was remarkable unity of purpose, particularly regarding views about previous research in the Torres Strait, the importance of community research ownership, and relevance to day-to-day community health issues.

Participants then proposed and discussed ideas as to what constituted community-driven research (Box 2), how it should be approached (Table 1), and what they saw as points of difference between community-driven research and institution-driven research (Table 2). Following discussion, participants started work creating their own proposals. Examples of 'one-pager' proposals are provided in the Supplementary Material. Proposals were then revisited each workshop day. By November, there were 11 proposals in development; one had already been successfully submitted

to the JCU-HREC. Soon after, the COVID-19 pandemic arrived; Torres Strait communities were effectively cut off from mainland Australia.

Anonymous participant feedback was provided by >80% of participants of each workshop (Fig. 1). Most responses were favourable. The form also had provision for free-form answers to questions: 'What were the best things about the workshop?' and 'What could be done better?'. Participants flagged the group discussions, multidisciplinary collaboration, and cultural perspective as most valuable. Some people wanted less structure, and some wanted more. Suggestions for improvement included more free discussion, better support between workshops, more consistent mentorship, and more community-based guest speakers and mentors. At the third workshop, participants combined to make a video covering the key issues. This is available online at https://youtu.be/t2z_86xOLX0 (Australian Institute of Tropical Health and Medicine (AITHM) and James Cook University 2019)

Box 2. What is community-driven research?

- When there are local issues
- When those issues are identified by local people on the front line
- When the front line people address those issues through their research processes
- When they come up with answers that matter
- When they turn the answers into practical changes and show they work
- Ensure that the community, the authorities, and the world knows about it

Workshop participants and facilitators were contacted in November 2020 to gauge the prospects of re-establishing the program, face-to-face and/or online. Most felt it was too early to re-commit and the program remained suspended until late-2021.

Discussion

A strong case for community-driven health research, as distinct from city-based institution-driven research, goes back more than two decades. A 2001 commentary by Ernest Hunter predicted that 'research will increasingly be localised, at a community level and thus responding to the particular circumstances of that community. Those communities will likely determine the research priorities…'. Hunter also pointed out that research will likely be solution-based rather than problem-based, quoting community members as, 'we already KNOW what the health problems are, we don't need to be told!' (Hunter 2001, p. 6).

This study describes the emergence of a community-driven research initiative, one borne of longstanding community frustration with the historical research 'burden' imposed from faraway academic institutions. The same issues have been widespread across northern Australia. Thomas *et al.* noted that, in the 1990s, '…the relationship between researchers and Indigenous organisations and community leaders remained volatile. Trust was often non-existent.' (Thomas *et al.* 2014, p. S16). In 2004, Professor Martin Nakata outlined the many problems and challenges ahead for Indigenous researchers before proposing a new way forward: 'We have a long road to travel; let's build it to last…'

Table 1. The local approach to health research.

Question	Answer	Do
• Ask the right question. • Is it simple? • Is it possible to answer? • Does it matter? • Has it been done before? • Do we have the resources?	• Not looking for problems but looking for solutions • Planning ways to get answers • Collaborate and collect accurate information using suitable methods • Evaluate the information • Put the story together and come up with answers	• Present the findings at community and outside meetings • Report up the line • Publish the results • Look for ways to implement the answer • Go fishing for a bit • Go to the next question

Table 2. Comparison between institution-driven and community-driven research.

Institution-driven research	Community-driven research
• Based at a distant university or institute • Led by academics: expert researchers • Experienced at applying for funds • Funds administered by the institution • Research questions arise in the institution • Key decisions made in the institution • Training of university researchers • Can call on community help • Data and intellectual property owned by the institution • Community feedback and translation are often inadequate	• Community-based • Led by community people: less 'expert' and more multidisciplinary • Little experience in applying for funds • Funds administered locally: importance of governance • Research questions arise in community • Key decisions made locally • Prioritises training of local people • Can call on institutional help • Data and intellectual property are owned by the community • An emphasis on community feedback and translation

(Nakata 2004, p. 5). The early 2000s saw the nascent promotion of research capacity building for Indigenous communities; a relevant guiding framework for Indigenous health workers was proposed by a Townsville-based group in 2006 (Bailey *et al*. 2006). In 2008, the National Health and Medical Research Council published a Roadmap for Aboriginal and Torres Strait Islander health research that included 'supporting Aboriginal and Torres Strait Islander Peoples in participating in research capacity building' (Fletcher *et al*. 2008). A 2009 study described workshops in the Aboriginal community of Yarrabah that sought to develop a university and community research collaboration whereby the community set the research agenda. It proposed a set of strategies for successful research partnerships (Mayo and Tsey 2009).

The past decade has seen a cascade of publications. Each contribution has offered ideas and suggestions, mainly based on returning control of research agendas to communities (Kendall *et al*. 2011; Jamieson *et al*. 2012; Kelly *et al*. 2012; Elston *et al*. 2013; Gwynn *et al*. 2015; Hickey *et al*. 2018; Ewen *et al*. 2019; Kim *et al*. 2021). In South Australia, the Wardliparingga Aboriginal Health Research unit developed an intensive research capacity strengthening program for community-controlled organisations together with program evaluation (Stajic *et al*. 2019). The same group then created an appraisal tool to assess the quality of health research from an Indigenous perspective (Harfield *et al*. 2020).

Two recent publications focused on the Torres Strait. Cheer *et al*. (2020) pointed to the complexity of household, extended family, and community relationships and the importance of community engagement. The authors stressed the need for playing the research 'long game' to ensure a sustainable model for the community health research agenda (Cheer *et al*. 2020). The communication by Kris *et al*. (2021) stressed that future research questions must be created by local people if they are to have meaning for them, and there must be a renewed focus on translation of research outcomes.

One outstanding feature of the Waiben workshops was the enthusiasm of the participants. This may have been because of the cultural framework and ways of interacting. Participants felt they could challenge and change the discourse at any time and they frequently did. For instance, at the outset of this initiative, the term capacity building was often used in meetings and correspondence, mainly by JCU-AITHM staff. Then, at the first workshop, a health worker declared, 'We've always had capacity, thank you. What we want is the opportunity.'. The term capacity building was never mentioned again. This incident also set the tone for future workshops.

Participants pointed out that workers on the frontline frequently came across obstacles in the system; 'they know what the system doesn't know'. They often had ideas about potential solutions and ideas outside the system. Community-driven research can improve local health outcomes. Rather than looking for problems, researchers can look for solutions that can be translated into day-to-day practice. Ideally, this approach would stimulate a paradigm shift, with increasing acceptance and organisational capacity to integrate research into the workplace. Hence, it is sustainable and supported at a team and organisational level. This would require leadership with the energy to drive workplace policies and procedures and to provide long-term support.

Defining community-based research was instructive for all participants, especially mainland-based JCU-AITHM representatives. When it came time for participants to generate their own research questions, a whole spectrum of local health issues sprang to the fore. Individual presentations to the wider group provoked vigorous discussion and practical suggestions. Most participants had never thought about creating specific and feasible research questions before; they were delighted by their new achievements.

The anonymous workshop feedback (Fig. 1) was positive. Most participants felt their contribution was valued. This bodes well for the future program. Participants made it clear that face-to-face interaction was a critical element and that online distance interaction is not an acceptable alternative. The nascent research proposals were put into suspended animation with the pandemic restrictions, but most are based on long-term community issues. They could be re-activated and further developed.

This approach faces a host of obstacles and challenges. In the Torres Strait, there is a history of health research scrutiny that goes back decades. Many people have long memories and negative opinions. Research fatigue can lead to indifference and resistance. There is also the challenge of geography and distance. The Torres Strait is truly remote; the seas and winds are unforgiving, and infrastructure resources are limited. Transport and communications can be precarious. Sustainable funding remains a perennial challenge for all rural and remote research endeavours (Cheer *et al*. 2020). There are also the complexities of regional ethics committees and getting informed consent in a cultural context. Intellectual property is another thorny issue. One enduring problem is skills drain or loss to the community when skilled-up people leave to pursue research careers elsewhere.

Conclusion

This initiative appeared to have enjoyed acceptance as an approach to developing a community-based and community-owned research agenda. Its premature suspension painfully highlights the challenges of long-term sustainability, a critical factor before downstream health benefits can manifest in the community. The immediate challenge is to get the program back on track and to secure ongoing funding while ensuring that the local community is at the helm. Should this approach prove successful, it may offer a model for research development in other rural and remote communities.

Supplementary material

Supplementary material is available online.

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Data availability. The data that support this study will be shared upon reasonable request to the corresponding author.

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