

# Health from the Grassroots, Listening to Mob: University-Based Aboriginal Researchers Collaborate with Aboriginal Communities to Identify Health Priorities

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## Article Info

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## Abstract

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There is opportunity for universities to actively engage with Aboriginal communities to participate, conduct and ideally lead responsible research that attends to community priorities and issues. The Health from the Grassroots (Grassroots) project sought to address an ongoing mismatch between university-defined and community-defined priorities in rural northern New South Wales (NSW), Australia. Grassroots, led by Aboriginal staff of the University Centre for Rural Health (UCRH), aimed at engaging Aboriginal communities in conversations to inform research priorities.

The Grassroots project was a true representation of collaborative research led by and for Aboriginal people. The team designed a local survey conducted yarning sessions with community members and used this information to visualize report findings. Community members were highly engaged in the consultation process and the “rich picture” continues to be used to further conversations about evolving health and research priorities.

The Aboriginal research team identified strengths and challenges faced by communities and health services in the region and centred community in decision-making for project design and direction. Challenges encountered include limited resources and time for team members to devote to the project outside of their substantive paid positions.

This paper describes the project vision, implementation, and research team lessons in the first years. Meaningful consultation to inform research action arose from the team’s deep-rooted relationships and identities as members of the community in which we live and work. Research priorities identified through the Grassroots project have been integrated into the ongoing work of the UCRH.

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## Glossary

**Yarning** Yarning is a word used by Aboriginal and Torres Strait Islander people that relates to communicating. To yarn is to spend time, listen, and talk. It's both a way of engaging and a methodology.

## Introduction

Aboriginal and Torres Strait Islander peoples are changing the way that research happens (Ewan et al., 2019). Their/our leadership has driven policy-level action that has increased funding for Indigenous health research and capacity building (de la Barra et al., 2009; Thomas et al., 2014) and policy-level guidance, directives and processes aimed at enhancing ethical research involving Indigenous communities (National Health and Medical Research Council; NHMRC, 2018a, 2018b). These changes are bringing a strengths-based approach that attends to a myriad of historical and contemporary problems in Indigenous health research. These problems include, for example, a tendency to focus on problems rather than solutions (Paul et al., 2010), to not undertake projects in partnership and thus have little benefit (Bainbridge et al., 2015), to be exploitative of Indigenous communities (Bainbridge et al., 2015; Laycock et al., 2011) and to contribute to ongoing mistrust of research by Indigenous people (Bainbridge et al., 2015).

Aboriginal peoples of Australia have endured much within the last 235 years, including forced removals of children, the introduction of disease, massacres of communities, stolen lands, incarceration and forced labour (Menzies, 2019; Paradies, 2016). While there is an array of data that illustrates current and historical health disparities of Aboriginal peoples (Australian Institute of Health and Welfare [AIHW], 2022; Smallwood et al., 2021), it is important to acknowledge the strength and resiliency that flourishes to this day (Bennett Green, 2019; Usher et al., 2021). Despite that, it is well known that research conducted in Aboriginal health has been conducted without meaningful and sustained engagement with Aboriginal researchers and community members (Bainbridge et al., 2015; Sherriff et al., 2019). This has yielded cries of “no research on us, without us” and the establishment of guidelines and standards for research about Aboriginal people to include Aboriginal

people in all parts of the process (National Health and Medical Research Council [NHMRC], 2018a, 2018b). Ideally, research for Aboriginal people is informed by, directed by, and led by Aboriginal people themselves.

The Health from the Grassroots project (Grassroots) centres the perspectives of Aboriginal people in the Northern Rivers area of NSW to explore what a healthy community is, what strengths-based factors create well-being, and priority areas for improvement. This project, led by a team of Aboriginal people, sought to understand what Aboriginal people in the Northern Rivers considered good health, what was working well in the community in terms of services and day-to-day life, and what needed to change to improve life and health.

## Project Background

The Northern Rivers region of NSW is Bundjalung and Yaegl country, where there are approximately 14 smaller language groups/countries (Figure 1). Each language group/country has their own dialect, lore, knowledge, and culture. In northern NSW, Aboriginal people account for 5.5% of the population (approximately 85,169 people) (AIHW, 2021). This amounts to almost double the state-wide average population of 3.5% for the rest of NSW.

**Figure 1**

*North Coast NSW Aboriginal Lands. Source : [www.planetcoroboree.com.au](http://www.planetcoroboree.com.au).*



In the Northern Rivers region, health care for Aboriginal people is delivered through a combination of community-controlled and government services, primary health care centres and hospitals that work together under the Aboriginal Health Partnership (NSW Health, 2015, 2022), although it is noted that some Aboriginal people use private primary health care centres solely for their health care (AIHW, n.d.). The goal of the AHP is to work towards provision of seamless health care from one system to another (NSW Health, 2015, 2022).

The Grassroots research team is comprised of Aboriginal staff from the University Centre for Rural Health (UCRH), which is a satellite school of the University of Sydney. All the team live and work in the communities where this study took place. At the UCRH, Aboriginal and Torres Strait

Islander staff form an organisation-wide caucus and are affectionally known as the CNC; “caucus not caucus”.

In 2018, the CNC team decided to undertake the Grassroots project to facilitate community conversations about health priorities and centralize Aboriginal perspectives in research processes. At a local level, we aimed to promote a process of change by documenting the perspectives of Aboriginal and Torres Strait Islander people living in Bundjalung and Yaegl country on their community health research priorities. Findings from Grassroots were intended to inform local service planning and research agendas for the region and the design of pilot research projects and grant funding applications. Our secondary aim was to build the capacity of local UCRH staff in establishing and implementing research responsive to community needs.

It is important to note that at the time of this study, the Northern Rivers was rebounding from record flooding in 2017, which was followed by the 2019–2020 Black Summer fires, considered among Australia’s “worst ever” fires (O’Kane & Fuller, 2022, p. 12). Then, while the data collection for the study was ending, the world was thrown into the COVID-19 pandemic. In early 2022 the Northern Rivers—as with other parts of NSW and southeast Queensland—experienced another record-breaking flood (Bath, 2022). The data collation and analysis for this project occurred between 2018–2020; the writing of the paper has taken longer; and momentum on establishing collaborative pilot projects has slowed. Yet we believe that our story and the key outcomes of our work are still valid and important to share. In the wake of the 2019–2020 fires and 2022 floods, it is perhaps even more important to share our story considering the effects of constant traumatic experiences for all people, and in this case Aboriginal peoples living on the NSW North Coast. By doing so, we hope to record and share our experiences of Aboriginal people working with Aboriginal communities despite ongoing challenges and give voice to the unique needs and ways of working required to continue similar work in the future.

## Methods

Aboriginal staff led the implementation of the Grassroots project with guiding support from non-Indigenous researchers who respectfully contributed their knowledge in line with the aims and direction of the project. The non-hierarchical nature of the CNC ensured that all voices were heard.

Communities across the region had input into this project, which informed subsequent research projects, and/or guided direction for the services who provide care and supports to Aboriginal people on the NSW North Coast. Another consideration was to ensure that the information we collected was accessible by all who participated so they are also able to have some ownership over the project and its outcomes.

Regular CNC and research team workshops/planning meetings were held to discuss the project design and implementation. An Aboriginal program manager and four Aboriginal community peer workers were employed from the region. Roles and responsibilities were divided among all CNC group members to share ownership of the project. The research teams shared lived experiences with the communities in which the study took place, and this helped ensure a shared understanding of the issues faced by the local communities. Integral to the project was ensuring adherence to cultural protocols and cultural integrity.

An iterative approach to engagement, data collection and implementation was used. Because team members had a busy work and travel schedule for their substantive positions, all-day workshops with the full research team were designed and conducted approximately every quarter. Workshops involved staff reflections, group debriefing, sharing key lessons, documenting project outcomes and new knowledge. After each data collection activity, the staff involved met to debrief on the data and approach. The team asked, “What was learned?”, “Are the needs of the community being met?”

and “How could this process be improved?” Using these insights, the approach was adapted for the next event.

This project received ethical approval by the Aboriginal Health and Medical Research Council (AH&MRC) Human Research Ethics Committee (HREC reference 1457/18) and meets the requirements of the National Statement on Ethical Conduct in Human Research (2007).

### **Approach to Data Collection**

A mixed methods approach was used for community engagement and included a survey and community forums. The survey was designed with a majority of the CNC (10 Aboriginal staff), to be strengths-based, capturing participants’ vision of a healthy community and priorities for improvement to reach that vision. In addition to socio-demographic details (age, sex, Indigeneity, residential community), the survey questions included:

1. What does a healthy community look like to you?
2. In your opinion, what are the top three priorities for the health and well-being of your community?
3. What things are working well to help keep our community healthy?
4. What issue, if improved, would have the biggest impact for your community?

The survey was available online and in paper form between July and September 2018. The online version of the survey, suitable for use on computers and mobile telephones, was generated using Qualtrics Provo (2018) software. Respondents were provided with a participant information sheet and advised that completion of the survey would signify consent to participate in the study. The survey was distributed via personal (e.g., word of mouth), social media (e.g., Facebook), and local organisational networks (e.g., newsletters). One of the key activities to generate participant responses was the team’s attendance at the local Aboriginal rugby league Knockout carnival held in Lismore. Members of the research team attended and approached people inviting them to participate in the survey. Over this period, with these approaches, approximately 192 people participated ( $n = 192$ ). A prize draw of A \$100 gift vouchers to spend in local businesses was offered to respondents who opted to put their details into the draw.

Five yarning sessions were advertised through service and community networks, each held in a different town in the region. Approximately 73 people participated overall, with varying numbers at each event ( $n = 73$ ). (See Table 1.) “Caucus not caucus” members and four local Aboriginal community peer workers who were employed to assist with recruitment and facilitation of the sessions attended. Peer workers were local to the area, trained in the purpose and aims of the project and mentored throughout to learn how to facilitate sessions, interview participants, and analyse qualitative data. Workshop participants were asked the same questions as survey participants, in a facilitated yarning-style format. Detailed notes were taken during the sessions, and subsequently compiled into a single document.

Four of the five community yarns were held as an open forum for anyone to attend. The fifth session was held with members of the Regional Aboriginal Education Consultative Group (RAECG) from Grafton, NSW to Tweed Heads, NSW. This was one of the first opportunities for our local community to share their stories and talk about their health experiences; some of the yarns were charged with emotion, and some participants shared negative stories for the first time. It was important for our team to listen to these stories, and to understand the aspects that could be reported in the results while ensuring the participants’ anonymity. Given that attendance at some of the sessions were low, the research team agreed not to over analyse the data and try to balance the

perspectives of community members with health worker perspectives.

**Table 1. Community Yarns—Attendees**

Location	Participant number	Community member	Works in health	Education/other
Grafton	6	4	1	1
Tweed Heads	11	10	1	0
Lismore	14	11	2	1
Ballina	12	9	3	0
RAECG	30	0	0	30
<b>Total</b>	<b>73</b>	<b>34</b>	<b>7</b>	<b>32</b>

## Group Analysis of Data

We analysed demographic data using Qualtrics, and qualitative survey data were downloaded onto, analysed, and summarised using NVivo (Version 12) qualitative data software. Responses to the prompt questions were typically provided in short phrases. For each question, we grouped responses into categories and subcategories (e.g., the top four priorities categories included specific health issues, health services, health behaviours, and needs of specific populations) and counted the responses for each. Two Grassroots members working in collaboration identified the issues that were particularly important for each forum. Using the survey and forum data, a summary for each region was prepared for further analysis in a day-long analysis workshop.

At the workshop, the Grassroots team split into groups of two, each taking ownership of a community whose forum they had attended. We began with a quiet reflection on the community, the forum, the community members who attended, how they felt listening to the community, and their key impressions. The groups then began to analyze the data provided, seeking to identify the most meaningful or pressing issue that emerged in the context of the forum yarn. Using their notes, they cut out snippets of data to map relationships between the top two key issues and others raised at the forum. For example, this snippet recorded from a forum was mapped to a larger issue of a need to increase awareness of community services and supports and how to access them:

Community members have expressed that there is a lack of basic information and referral forms from Aboriginal community-controlled organisations which could inform the community about services, products and resource which could make life easier like, housing support, drug and alcohol services, employment and training support and opportunities, job awareness, program awareness, transport, etc.

By constantly referencing data to the map, the groups moved back and forth to abstract and create themes (Vaismoradi et al., 2016). After several hours of work, the groups identified the two main themes that encapsulated the forum discussions and survey data and represented priorities for each community. They endeavoured to identify strengths for each community but found this difficult given forum conversations had focused on deficits, so groups looked at these deficits as areas of opportunity. Finally, each group shared back with the full team as a way of comparing findings. We discussed the identified themes and raised methodological issues in the data collection.

## Reporting to the Community

Reporting back to community and keeping community involved with the findings of the study was paramount, after all, the data collected belongs to them. The team decided to disseminate information via a visualisation of findings (Figure 2), and a series of in person reports to groups. Visualisations align with and uphold Indigenous research methods and storytelling approaches that precede Western research methodologies (O'Connor et al., 2023). Further, we chose to use a visual approach given previous work by project members to establish a “rich picture” as an effective and meaningful method in disseminating complex ideas (in this case, reconciling data that focused on deficits with our intention to progress in a positive, affirming manner) that invites collaborative interpretation (Conte & Davidson, 2020).

To develop pictures that celebrated a vision of a healthy community, we drew on the key strengths and priorities identified for improvement during analysis within each region. Working with a local graphic artist, these visualisations were laid out geographically, tying them to place. We choose to depict the key findings around deficits as priorities for future action, framing these as priority opportunities for improvement. Additionally, we employed a local Aboriginal artist to develop drawings to incorporate into the final product. The team felt that including small flora and fauna totems specific to each community would enable members to identify with the posters and the information they provided. This “rich picture” was then shared at subsequent community events and conferences as a way of reporting-back to community about the findings generated from the first stage of the project. The purpose of using this “rich picture” was to highlight the key findings, while also allowing our audience to bring their own interpretations and insights to the image (Conte & Davidson, 2020). In this way, the “rich picture” acted as both a tool to communicate findings, and a tool to engage deeper conversation about community priorities and the stories behind the images.

### Figure 2

*Health for the Grassroots “Rich Picture” Depicting Findings from Surveys and Yarning Sessions with Communities.*



## Results

### Outcomes of Grassroots Consultation and Project Activities

The “rich picture” is a large-scale visual map of the Grassroots project area from Tweed Heads to Grafton NSW, which features an aerial landscape view and key landmarks that enable community members to identify their local areas. Protective factors and cultural activities described by community members as strengths are depicted in the illustrations. These protective factors include social connectedness, traditional arts and crafts, culture and language, being on Country, responsive health care services, and cultural camps or gatherings.

At the bottom of the picture, we list the priorities identified by communities and through the analysis. These include: 1) access to culturally safe services—especially in mental health, drugs, and alcohol treatment, 2) increase service collaborations and effective communications with community, 3) strengthen connection to culture in programs, 4) address all forms of violence within community, 5) target children and youth, 6) target socioeconomic factors—e.g., employment, housing, and education. Subsequently, our findings were further confirmed by a needs assessment conducted by the North Coast Primary Health Network (NCPHN) (2019). It also identified health priorities in the Northern Rivers as: access to culturally appropriate services, high rates of mental health episodes, trauma, youth suicide and preventable chronic disease (NCPHN, 2019).

We presented the picture in large scale and as small handouts at multiple community gatherings, presentations, and to services. Anecdotally, feedback was overall positive. Community members were drawn to the image at community events and came to talk with us about their experiences and hopes for the future. It was a useful tool to begin conversations between university-based Aboriginal researchers and community members who spent time talking with us, learning about our research, and sharing their stories. It was also presented at the AHP to prompt discussion and reflection.

## Limitations

As noted earlier, the Grassroots project was challenged by the timing of local and global disasters which took time away from project activities and our ability to seek additional resources.

The response rate to the surveys was lower than we hoped, and we were unable to host as many forums as we would have liked. However, the conversations held throughout the project were particularly poignant. Forum participants were generally Elders, and though not a representative sample of the community, Elders passionately expressed their hopes for the younger generation and a desire for priorities to focus on their needs. This perspective and guidance from our Elders felt particularly important to guiding our next steps and priorities for future projects.

## Discussion

### Lessons

The Grassroots project, while small, has added to the local Aboriginal health research agenda by putting community opinion and needs first. The projects which have emanated from, and address, Grassroots priorities are themselves designed to incorporate local community decision-making in their direction and implementation.

Current projects informed by Grassroots research include:

- the development of a virtual reality learning environment that shares patient experiences of racism in the health care system
- a workforce research project with local Aboriginal community-controlled health services and other primary care and hospital stakeholders
- a project which aims to develop community-led interactive digital story maps of environmental changes and culturally important places which will be used to develop local community climate adaptation plans with relevant agencies and service providers.

Our approach to implementing the Grassroots survey and yarning forums was a valuable way for our team of Aboriginal researchers to apply our local knowledge and identities to working with our communities. The outcomes have guided research priority settings that address many of the issues raised by community. As researchers, it is also important to reflect on each study, each process, each yarn. We share the lessons in working in this manner, hoping to support other researchers in their journeys.

### **Building—or dissolving—partnerships with stakeholders**

From project inception, it was important to the CNC to have the support and buy-in from key local organizational stakeholders. The project manager engaged with many local health service providers about the objectives of the Grassroots project, community led discussions on health issues and potential research partnerships at both the beginning of the project and then as a part of the feedback processes. As the project progressed, we experienced tensions from various competing priorities brought forward by the organizations involved. In some cases, there was pressure to adapt Grassroots to meet other organizations' priorities. In other cases, and perhaps due to a lack of formal, external funding mechanisms or certainty of future funding, commitments by partners were not met. Despite hesitancy from some service providers within the AHP, to ensure that our commitments to community were met we kept to our original vision and directed our energy and focus to services where collaborative spirit was evident. As both the institutional face of Grassroots, and members of the communities, our obligations and responsibilities to community were multi-faceted. This put significant pressure on our work, personal reputation, and sense of responsibility to meet commitments.

It is also important to acknowledge that there were occasions when community members attended who also worked for local partner organisations. For some, it was hard to separate their work identity from their personal identity while attending as a community member. The CNC team has previously identified this difficulty as a recurring experience when engaging with local communities about health.

### **Managing community expectations**

It was important to manage community expectations from the initial consultation. Small actionable items as well as larger systemic issues more conducive to future research projects were expected to be uncovered and there were no funds for these. Any further projects would need to be designed with community and relevant stakeholders, and funding would need to be sought. Ultimately, the role of this project is to gather evidence to provide a platform for community voices and help advocate and link services together to respond to community concerns and needs.

## Managing project staff expectations and safety

We began and ran this project with enthusiasm and vision for an opportunity to work with and for our communities. As members of the communities ourselves, barriers we encountered to progress—though typical of projects such as these—took on a different kind of weight given our personal connections. For most CNC staff, Grassroots was extracurricular to their substantive positions. Therefore, the needs of employment-related obligations with Grassroots project needs felt particularly conflicting.

Further, as the project developed, we became aware of other challenges that are likely unique for a team that is embedded in community. During community forums, difficult topics were raised by community members facing the impact of current and historical traumas. While we had a safety protocol in place for our participants, it was not until we debriefed post-forum that we realized the vicarious trauma we ourselves experienced by hearing, empathising with, and in some cases, sharing these experiences. This led us to develop safety protocols and debriefing meetings to ensure that we and the peer leaders were properly supported in doing the work.

## Balancing of timing with momentum

As has been shown numerous times in community-engaged literature (Hunt, 2013; Israel et al., 1998), substantial time is needed to build relationships and plan for implementation. We operated on a shortened, six-month timeline that coincided with the resources available for employing the Grassroots project manager and community peer workers. And although we had the advantage of having established relationships within the community, we felt taxed by the pace of the project. With more time, we could have established clearer relationships and expectations with organization-level partners, had more thorough engagement with community, and importantly—more time for careful reflection, thinking and planning.

We were, however, fuelled by interest from the community. As community members became aware of and enthusiastic about the project, we were driven to match their interest and momentum as the project grew. It was challenging to slow down when community were keen to progress. On reflection, this community interest reflects a strength of our project and our approach but underscores the importance of adequate resourcing to ensure that community dialogue and associated projects can be continued.

## Conclusion

While the Health from the Grassroots project continues to successfully inform priorities in Indigenous health research, it was a labour of love for everyone involved. Team meetings had to fit between other personal, professional and community obligations and combined laughter and fun with hard conversations. Yet somehow, despite limited resources and competing priorities, the work still got done. The individuals who make up organisations have important roles to play in their local communities, which are not reflected in their formal job descriptions. They bring unique opportunities to build bridges between communities that can add value to the mission of an organisation, provided they are sufficiently supported to do so. Our vision for future endeavours is that initiatives such as ours will be seen as value adding and resourced as part of the mission of the research institutions involved.

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