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"You didn't just consult community, you involved us": transformation of a 'top-down' Aboriginal mental health project into a 'bottom-up' community-driven process

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Abstract

Objective: Recently, there has been a consistent call for Indigenous health research to be community-driven. However, for a variety of reasons, many projects, such as the one featured here, start as 'top-down'. Using ten accepted principles for Aboriginal health research, the present article illustrates how a top-down project can be transformed into a 'bottom-up' community-driven project.

Method: A table of examples is provided to show how the ten principles were translated into practice to create a bottom-up process.

Results: We suggest that key elements for creating a bottom-up process are iterative conversations and community involvement that goes beyond notional engagement. A feature of community involvement is generating and sustaining ongoing conversations with multiple levels of community (organisations, health professionals, Elders, community members, project-specific groups) in a variety of different forums across the entire duration of a project. Local research teams, a commitment to building capacity in the local Indigenous workforce, and adequate timelines and funding are other factors that we hypothesise may contribute to successful outcomes.

Conclusion: The article contributes to a much-needed evidence base demonstrating how appropriate structures and strategies may create bottom-up processes leading to successful outcomes.

Keywords: Community engagement, Indigenous mental health, Aboriginal health, Community-based participatory research, Community involvement

To address past experiences of exploitation in research with Aboriginal and Torres Strait Islander Peoples, there has been a consistent call in recent times for Indigenous research to be community driven.[1–3] These principles have been enshrined in government and health policy documents.[1–3] However, projects involving Aboriginal and Torres Strait Islander Peoples are often initiated by governments and other agencies without seeking community involvement, and therefore by default become top-down processes.

The purpose of this article is to identify how one organisation, the University Centre for Rural Health (North Coast) (UCRH), addressed the imperative to transform a top-down government initiative into a community-driven research project. The article is designed to answer the call for 'the development of a comprehensive evidence base for appropriate governance structures and procedures in Aboriginal and Torres Strait Islander Health Research' (p.241).[1] Using the principles for community governance of health research articulated by Jamieson et al.[4] and Gwynn et al.,[1] we illustrate how

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community-driven research was created which was 'relevant, effective and culturally respectful' (p.19).[4]

The project was part of a Federal government strategy, e-Mental health in practice (e-MHPrac), to train health professionals in e-mental health practice (see www.emprac.org.au). e-Mental health refers to the use of electronic media such as apps and online therapy programs to deliver evidence-based psychological therapies to people who often may not be able to access, or wish to access, face-to-face therapies. The health professionals identified by the government tender as potential recipients of e-mental health training were GPs, allied health professionals, and Aboriginal Health Workers.

The 3-year e-MHPrac initiative, undertaken for good reasons (e.g. very promising Australian e-mental health research; the need to translate research into clinical practice) was tendered in early 2013. Based on our previous work with Aboriginal counsellors and e-mental health,[5,6] UCRH was invited by the project leaders, Queensland University of Technology (QUT), to be one of five partners in the national project. UCRH's role, together Menzies School of Health Research and QUT, was to design and deliver e-mental health training for Aboriginal health professionals. By the time we were engaged in the project, we had just two weeks to conceptualise and design our part of the tender! Given the tight time frame, we were only able to have brief conversations about the project with two local Aboriginal services. Although from the outset we were clear that our research methodology would be community-based participatory research,[7–9] meaningful community engagement prior to submission was impossible.

In this paper, we identify how we set about transforming a top-down process into a bottom-up community-driven process. To do this, we have framed the paper in terms of 10 identified principles for conducting health research among Indigenous Australian populations.[4] These principles, which have been adopted by other researchers,[1,6] are identified in Table 1, together with brief descriptions of how they were translated into practice.

As we aim to demonstrate, each of the principles – with the exception in the initial instance of Principle 1 (due to the top-down tendering process) – was addressed within our the community-based participatory research (CBPR) protocol.[7–10] CPBR has been strongly endorsed as a culturally appropriate research strategy for Aboriginal and Torres Strait Islander Peoples.[9,10] It 'harnesses community wisdom in an equal partnership with academic methodological rigor throughout the research process' (p.350),[8] drawing on widespread community involvement at all stages of the research process. We therefore perceived CBPR to be highly consistent with the 10 principles in Table 1.

Our approach to community involvement (a term we prefer to 'engagement' – see below) has been to harness the wisdom of the Aboriginal and Torres Strait Islander community from across the region throughout the duration of the project. We have sought to develop rapport and to build rich, dynamic working relationships.[1,4,9,11,12] Processes were established that would facilitate ongoing dialogue and generate feedback loops of accountability between the research team and the community.[9,11] See Table 1 for details.

All elements of the project gained ethics approval from the Aboriginal Health and Medical Research Council (NSW) and the Northern NSW Local Health District.

The 10 Principles in Practice

The aim of the research component of the project was to design and evaluate a culturally appropriate training program in e-mental health strategies (e.g. use of apps and online therapy programs), which would enhance the skills of service providers for Aboriginal and Torres Strait Islander people. Central to the design of the program was the community's active participation in advisory groups, learning circles and community forums, which created opportunities for ongoing dialogue and feedback loops. Through these processes the community took charge of the design, content, structure and conceptual framework of the new training program (see Table 1). In the process positive outcomes were achieved. For example:

- Feedback from the Learning Circles resulting in the development of the first Indigenous online therapy program (see www.mindspot.org.au);
- Feedback from Advisory groups ensured culturally appropriate training in application of e-technologies;
- Input from the Ngayundi Health Council (elders) led to the inclusion of culturally appropriate post-training supervision and a change of focus in the program from 'e-mental health' to 'e-social and emotional wellbeing'.

Table 1 provides examples of how the 10 principles were translated into practice to create a bottom-up process. We suggest that the implementation of these principles has been fundamental in enabling the top-down Federal government-initiated e-MHPrac project to be transformed to a bottom-up community-driven approach.

Discussion

The discussion focuses on factors that we hypothesise may have been particularly important in assisting the bottom-up process. These are identified in Figure 1.

Conversations

One of the most important factors in involving the community was the conversations between the researchers and community, which enabled the building of confidence and trust in one another. We characterise these conversations as involving *an iterative process over an*

Table 1. The 10 Principles in Practice

10 Principles for Research with Aboriginal and Torres Strait Islander Peoples	***The 10 Principles in Practice***
Essential Principles	
1. Addressing a priority health issue as determined by the community.	Training Aboriginal health professionals in e-mental health was not one of the community's priorities at the start of the project. However, everyone recognised that better mental health was a priority health issue. Therefore, a process of iterative dialogue was developed across multiple levels of community in order to discuss the rationale for training in e-technologies, and to shift from a top-down model to a community-driven project. Included in the dialogue were key community organisations (e.g. the Ngayundi Aboriginal Health Council), as well as structures established specifically for the project: Advisory Groups to oversee the project, and Learning Circles to try out and provide specific feedback about e-technologies. Through ongoing dialogue, the community came to recognise that the potential of e-technologies – especially for young people. This led to support and endorsement for Aboriginal health professionals to 'get with the program' by training in e-mental health.
2. Conducting research within a mutually respectful partnership framework.	Central to the mutually respectful partnership framework has been active community involvement across the NNSW region. Examples of this mutually respectful partnership include: • Respected local Aboriginal health professionals have been employed within the project as researchers, trainers and coordinators. • Community members of Learning Circles have been paid as consultants for their expertise in providing feedback about apps and online programs over a 5-week period. • The Ngayundi Aboriginal Health Council (mainly local Elders) and Advisory groups, including managers of NGOs and AMSes and community members of different ages, have consistently provided advice which has been incorporated to improve ethics applications and research methodologies.
3. Capacity building as a key focus of the research partnership, with sufficient budget to support this.	A large proportion of the budget has been specifically directed towards capacity building. Over the project period we have employed eight team members: four Aboriginal, four non-Aboriginal. One member of the Aboriginal team has registered for a Ph.D. More than 20 other members of the community have been paid as consultants (e.g. in Learning Circles and Advisory Groups). Three of the team have been seconded from other organisations without losing ongoing stable employment. They have developed their skill base and been supported to attend professional development opportunities, e.g. culturally appropriate peer supervision training. Advisory group and Learning Circle members have developed new skills and confidence. Some have gained better jobs, or engaged in new training opportunities.
4. Flexibility in study implementation while maintaining scientific rigour.	Community feedback has been central to the design and implementation of the study, which has undergone several revisions and extensions as a result. For example, Advisory group feedback led to: • the Learning Circle methodology being changed from the original proposal. • a module on technological skills development (using iPads, Apps, new technologies) being included in the training package (particularly for older participants). • the provision of culturally appropriate supervision.
5. Respecting communities' past and present experience of research.	Aboriginal communities' past experience of research has typically been 'tick-and-flick' consultation, lack of focus on community priorities, lack of appropriate recognition for their expertise, and failure to employ or provide professional development opportunities for Aboriginal and Torres Strait Islander Peoples. We have been mindful of these issues and sought to address them (see 1–4 above).

(Continued)

Table 1. (Continued)

10 Principles for Research with Aboriginal and Torres Strait Islander Peoples	*The 10 Principles in Practice*
Desirable Principles	
6. Recognising diversity of Indigenous Australian populations.	The design of the national project takes into account the diversity of Indigenous Australian populations. For example: location-specific e-mental health/wellbeing training programs have been developed and delivered each pilot site (Northern NSW, Northern Territory and Far North Queensland). Within the Northern NSW project, there are separate Advisory Groups and Learning Circles in our two primary sites (Lismore and Tweed Heads regions). We have consulted with community/health professionals in our 'extension' sites (Grafton and Coffs Harbour).
7. Ensuring extended timelines do not jeopardise projects.	Project timelines are often jeopardised by delays – for instance in ethics approvals, community consultations, employment of staff, unforeseen community-based events (e.g. funerals, community meetings) etc. Therefore project planning needs to take into account these challenges. We recognised community consultation as fundamental to addressing a top-down initiated project, and achieving a community-driven initiative. Therefore, we negotiated with the Commonwealth funders to allow that the first 12 months of the project would be entirely focused on creating bottom-up processes for community involvement and input.
8. Preparing for Indigenous Leadership turnover.	The issue of Indigenous Leadership turnover has been addressed by involving many people from diverse and wide-ranging parts of the community. This has deflected excessive commitment from just a few key stakeholders. For example: Advisory Group membership in Tweed and Lismore is flexible and fluid, including between 15 to 20 people in each group. Starting off with a larger membership ensures that pressure to attend meetings does not burden just a few key stakeholders.
9. Supporting Community ownership.	As above (e.g. points 1–5) there has been substantive community input and ownership. For example: • The Aboriginal trainer/supervisor, and two other Aboriginal Coordinators have been integral to presentations and workshops to over 30 organisations in the region. • These workshops have supported community ownership by enabling community to make informed decisions about the potential role of e-mental health strategies. • Advisory Groups have included members from wide-ranging health organisations and community groups with 95 % of Advisory Group members being Aboriginal and Torres Strait Islander People.
10. Developing systems to facilitate partnership management in multicentre studies.	Within the Northern NSW arm of the study, the Aboriginal and non-Aboriginal staff attend meetings in Tweed and Lismore, ensuring crossover of information and equitable, transparent processes. Similar procedures (e.g. for recruitment, payment) governed by our ethics applications and facilitated by the Aboriginal coordinators have been used in both centres. In the first two years of the national project, the three sites were largely independent (though communicating regularly). However, in the final 12 months, the three sites linked closely to develop a manual for e-mental health training program for use by other organisations.

Figure 1. Factors which may have been particularly important in transforming a top-down process to bottom up.

extended period of time. For instance, in our first meeting with the Ngayundi Aboriginal Health Council (comprised primarily of community Elders), Council members raised several significant concerns about the project – for instance, stating that they were concerned that young people were already spending too much time on mobile phones and were disconnecting from community. Why would Ngayundi Council want to endorse a project that involved greater use of new technologies? As the researchers on this project, we went away from that first meeting with a set of questions from the community that needed addressing. We took these concerns/questions to our national project partners and to the two local advisory groups for discussion. After several months of ongoing dialogue, the Council's concerns were addressed and these changes were incorporated into the project design. The Council were satisfied not only with the amendments, but also with the process undertaken to ensure that the community's voice was heard and enacted. Formal endorsement for the project was then granted.

Community involvement

Terms like 'community consultation' and 'community engagement' are now routinely used in articles to describe a variety of processes of engagement with Indigenous communities. Sometimes these are 'tick-and-flick' processes, sometimes they have more depth. Following on from the "You didn't just consult community, you involved us" comment of an Advisory Group member, which is part of the title of the paper, we favour the term 'community involvement' to describe these processes, which have:

(i) Involved key organisations (e.g. Ngayundi Health Council, Aboriginal-controlled Medical Services, Aboriginal Interagencies)

(ii) Involved a wide range of health professionals, community members and stakeholders (e.g. health professionals from a variety of different organisations, community members, Elders, young people, across the whole region)

(iii) Created project-specific Advisory groups (Advisory groups, Learning Circles)

(iv) Engaged the community over the whole duration of a project (not just the start)

Local research team

The project has benefited from established pre-existing relationships between the research team, managers of health services, and the community. Unlike many Indigenous research projects, this meant that the research was undertaken by regional and rural researchers (Indigenous and non-Indigenous) living and working locally. We suggest that project funders should recognise the fundamental importance of local researchers with ties to the community to the delivery of successful projects.

Building capacity of the Indigenous workforce

The project has clearly helped to build capacity in the local Indigenous workforce, which has reinforced its value to community (see Table 1, point 3).

Workable time frames and adequate funding

We were given three years to undertake the project and had an adequate budget that enabled us to build a community involvement process and local capacity. We note our good fortune here, and recognise that many other Indigenous projects are not sufficiently well funded or given adequate budgets to enable these kind of strategies.[12]

Conclusion

We hope that the present article is a contribution towards the development of 'a comprehensive evidence base for appropriate governance structures and procedures in Aboriginal and Torres Strait Islander health research' (p.241);[1] that it adds to the literature by suggesting ways to turn a top-down into a community-driven bottom-up project; and that it goes some way to indicating what community involvement might look like when grounded in the 10 principles.

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Disclosure

The authors report no conflict of interest. The authors alone are responsible for the content and writing of the paper.

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