

ORIGINAL RESEARCH

Using a participatory action research framework to listen to Aboriginal and Torres Strait Islander people in Australia about pandemic influenza

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ABSTRACT

Introduction: This article describes the use and effectiveness of the participatory action research (PAR) framework to better understand community members' perceptions and risks of pandemic influenza. In 2009, the H1N1 influenza pandemic affected Indigenous populations more than non-Indigenous populations in Oceania and the Americas. Higher prevalence of comorbidities (diabetes, obesity, asthma and chronic obstructive pulmonary disease) as well as pregnancy in Indigenous communities may have contributed to the higher risks of severe disease. Social disparity, institutionalised racism within health services and differences in access to culturally safe health services have also been reported as contributors to disadvantage and delayed appropriate treatment.

Methods: Given these factors and the subsequent impact they had on Australian Aboriginal and Torres Strait Islander communities, the authors set out to ensure that the Australian national, state and territory pandemic plans adequately reflected the risk status of Aboriginal and Torres Strait Islander peoples and promoted meaningful engagement with communities to mitigate this risk. A national study explored the views of Aboriginal and Torres Strait Islander people and their experiences with H1N1 and used a qualitative PAR framework that was effective in gaining deep understandings from participants. Aboriginal and Torres Strait



Islander community-controlled organisations and health services were involved in the implementation, interpretation and monitoring of this project.

Results: As a result, important features of the implementation of this PAR framework with Aboriginal and Torres Strait Islander communities and organisations emerged. These features included the importance of working in a multidisciplinary team with Aboriginal and Torres Strait Islander researchers; the complexities and importance of obtaining multi-site human research ethics approval processes; the importance and value of building the research capacity of both experienced and novice researchers in PAR; the need to use localised sampling protocols; and the process of undertaking a collective research process and enacting action research and feedback.

Conclusions: The most effective responses of this project were embedded in pre-existing relationships with individuals within organisations that had been established over a long period of time between Aboriginal medical services and investigators; however, research relationships established specifically for the purposes of the project were less successful because of changes in personnel and organisational support. The participatory approach used in this study has the potential to be applied to vulnerable populations in other countries.

Key words: community engagement, Indigenous health, methodology, pandemic influenza, participatory action research, research capacity.

Introduction

A study using participatory action research to explore Indigenous Australians' perspectives of H1N1

This study's multidisciplinary team of researchers set out to influence change in the Australian national pandemic plans. A national study was conducted to explore the views of Aboriginal and Torres Strait Islander people about their experiences with H1N1 using a qualitative participatory action research (PAR) framework¹. Aboriginal and Torres Strait Islander community-controlled organisations and health services were involved in the implementation, interpretation and monitoring of the project. The research team designed the study to have PAR framework across multiple sites in Australia. The study used qualitative research methods to collect and analyse information from Aboriginal and Torres Strait Islander participants who had experienced the 2009 H1N1 pandemic (H1N109). Community-based researchers were selected from all participating communities and trained in qualitative research methods. The overarching principles were to develop and maintain strong relationships with communities and organisations, to engage in genuine and

open dialogue about the research and to align with national ethical standards. The aims of the study were to:

- identify barriers to the implementation of current containment strategies for H1N109 in rural and remote Aboriginal and Torres Strait Islander communities
- develop culturally appropriate and effective containment strategies for H1N109 and future pandemics in these communities, modified where possible by the experience of the pandemic.

The H1N109 influenza pandemic resulted in higher incidence in New Zealand Maori and Pacific Islanders and greater morbidity in Indigenous populations in the Americas, New Zealand and Australia². Hospitalisations and deaths from H1N109 were three to six times more common in Indigenous peoples than non-Indigenous peoples living in the same regions³⁻⁷. A higher prevalence of diabetes, obesity, asthma, chronic obstructive pulmonary disease and pregnancy in Indigenous communities may have contributed to the higher risks of severe disease. Social disparity, institutionalised racism and differences in access to culturally safe health



services also contributed to delayed appropriate treatment^{3,8}. However, a new study has identified a possible biological explanation for greater susceptibility in Australian Aboriginal people to various strains of influenza⁹.

During the 2009 H1N1 pandemic, the national pandemic influenza plans frequently masked or neglected the lives, needs and interests of disadvantaged groups within the population^{10,11}. The result of this neglect was to further disadvantage the people most likely to require protection from a pandemic¹².

Health researchers have long advocated better understanding of important social aspects of the prevention and response to infectious disease outbreaks, including influenza. However, published research and understanding in this field falls significantly behind that of non-communicable diseases¹³. Social aspects of communities such as cultural values, importance of norms, strong family ties and social networks may impede or facilitate pandemic risk reduction efforts¹⁴. Understanding these values and planning from the perspective of the at-risk population is important, but for this to be effective it is essential that the planning is done with respectful engagement of vulnerable communities¹⁵.

Choice of methodology

PAR is recognised as a method of research that may be more acceptable to Australian Aboriginal and Torres Strait Islander people, and was supported by the community research partners involved in this project¹⁵⁻¹⁷. PAR differs from other research methods in that it seeks to bring about positive change, not simply investigate or describe an issue. In addition, the research process is based on equal and collaborative involvement of the community and participants affected by the issue¹⁸⁻²¹.

Historically, research on Aboriginal and Torres Strait Islander peoples, and Indigenous people in other countries, has been deemed inappropriate as researchers sought to collect and describe the data without providing benefits to the people or communities researched²². The Aboriginal researchers employed on this project were acutely aware of the practice

of researchers taking information from community members without giving anything back¹⁹.

PAR offers a way to make the research meaningful for a community¹⁸, being based on an action cycle that assists in improving processes for addressing issues from the communities' perspectives^{23,24}. The research team applied a PAR approach that was collaborative, participatory and based on equal partnerships between Aboriginal and Torres Strait Islander community members, organisations, research assistants and researchers. It was driven and owned jointly by the community and the researchers, and involved a two-way respectful conversation that fed into both the process and the outcome of the research. Rather than a linear model of researcher-led data retrieval and analysis, PAR is a cyclical process of planning, acting, observing and reflecting (Fig1). This design enabled each new collection of data in the H1N109 project to be grounded in reflections formed on the previous data.

Historically, research has not been a positive experience for Indigenous communities²⁵. Researchers have a responsibility to cause no harm, but traditional forms of research have been a source of distress for Indigenous peoples due to inappropriate methods and practices^{23,26}. PAR offers a way to make the research meaningful for the community and enables an action research cycle that assists in improving processes for addressing issues, such as pandemic influenza, from the communities' perspectives.

PAR is increasingly recognised as useful for health research in marginalised groups like Indigenous populations²⁷. It has potential to reduce the negative effects that conventional research has had on Indigenous peoples^{28,29} by recognising the community knowledge power base.

The recognition that power is directly related to knowledge lies at the very heart of the collaborative participatory research project. For public health researchers who are committed to reducing the health inequalities that are associated with social disadvantage, this approach offers a strategy that embraces self-determination, encourages and even demands ongoing consultation and negotiation, and



*provides opportunities for capacity-building and empowerment in the communities involved in the research*³⁰.

Importantly, when communities seek control of the research agenda, and actively engage in the research, they are establishing themselves as more powerful agents²⁷. With the increasing use of PAR approaches to address public health issues, there is potential for bridging the gap between research and practice in addressing social issues and creating conditions that facilitate people's control over the determinants of their health³¹. A key strength of PAR is the partnership between participants' real world knowledge and researchers' methodological expertise³¹. Partnerships that are formed with marginalised and vulnerable populations need to ensure that concepts of cultural humility and cultural safety are integrated, and maintain mutual respect and trust³¹. PAR stages included engagement with community groups, organisations, individual and group interviews, yarning (talking) circles and community reports. Strong community engagement at different sites meant that the engagement processes, although based on standard principles of research, was adapted to the differing local contexts and stakeholders.

Methods and results

During this study, the research team identified important and novel aspects of the methods.

Multidisciplinary team and Aboriginal and Torres Strait Islander researchers

The research team comprised senior and early-career researchers, Aboriginal and Torres Strait Islander and non-Aboriginal and Torres Strait Islander people. Members came from a wide variety of disciplines including medicine, veterinary science, epidemiology, public health, anthropology, health promotion, nursing and education. In common was a commitment to, and a long history of working on, applied research prioritised with Aboriginal and Torres Strait Islander communities. Members also shared a value of social justice for Aboriginal and Torres Strait Islander people. All researchers had established relationships with at least one other person on the team and some had long histories of working together. There was an assumed complementarity of

knowledge and skills in the team, an assumption that was tested and confirmed as the research progressed.

Aboriginal and Torres Strait Islander researchers were recruited from their local communities across Australia: three were employed in community-controlled health services; two were government health employees, and four were community members with diverse employment histories. Researchers of both genders were employed at each research site and included senior community members and young people. These researchers had different knowledge and skill sets and different educational backgrounds¹⁷. Training workshops were held in various locations to train Aboriginal and Torres Strait Islander researchers in qualitative research methods. These workshops were led by very experienced qualitative researchers who had worked in remote Aboriginal communities for many years. The Aboriginal and Torres Strait Islander researchers collected qualitative data, advised on cultural and community protocols, and the research team collectively analysed this data.

Ethics

Human Research Ethics Committee (HREC) approvals were granted from universities and state authorities. HRECs included James Cook University (H3546) in Queensland, the Aboriginal Health and Medical Research Council (746/10) and the Hunter New England HREC (09/09/16/4.01) in New South Wales, and the *Western Australian Aboriginal Health Ethics Committee* (291 06/10). Under ethical research principles involving Aboriginal and Torres Strait Islander participants the additional ethics criteria required can be methodologically challenging in a number of ways. Gaining documented approvals and support from community-controlled organisations, local government and other agencies was required for this study. Additional ethical challenges included ensuring that local community protocols for consultations were followed and that data had local ownership³². This meant that in 2009 multisite approval processes across jurisdictions and universities were necessary. Additionally, all ethics applications had to document how the project adhered to specific ethical principles centered on spirit and integrity and included responsibility, respect, reciprocity, equality and survival and protection³².

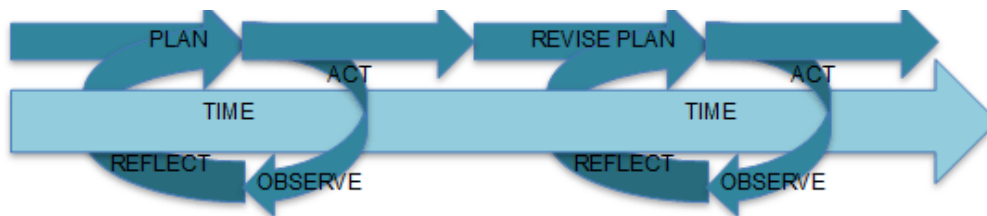


Figure 1: Participatory action research²³.

Capacity building

An important foundation for the research strategy was the capacity building of all team members involved in PAR. A series of training workshops that focused on qualitative research methods, data collection and data analysis were conducted in three of the research sites in Australia. These workshops were conducted at key points of the research journey, just in time for it to be relevant and meaningful to the researchers³³. The training workshops were attended by chief and associate investigators, and research assistants, at various locations. This collaborative process highlighted another two-way learning approach to the research which placed equal value on respecting the values of Indigenous and non-Indigenous members' cultures, knowledge, processes and worldviews³⁴.

The multidisciplinary nature of the research team and the various stages of their research careers necessitated different levels of support, mentoring and capacity development. The research team members benefited from their learning from the Aboriginal and Torres Strait Islander researchers by challenging their own assumptions and approaches to research. At the same time, community researchers gained a better understanding of the formal research process and the opportunities available from the higher education system. Support, guidance and mentoring provided the community researchers with opportunities to help them plan their future careers and education pathways.

Sampling

As is appropriate for this type of qualitative research, the Aboriginal and Torres Strait Islander researchers operated

within existing social and work networks to identify study participants. This approach enabled participants from across the communities to be involved. A purposive sampling technique was used in the selection of participants, which included Aboriginal community-controlled health services staff and Aboriginal and Torres Strait Islander community members of mixed ages and genders.

Collective research process

The PAR cycles included engagement with community groups, organisations, individual and group interviews, yarning circles and feedback presentations for community reports. The sampling framework and data collection questions were developed by the research team as part of the training workshops. A collective and collaborative process was used involving all researchers at all stages of data collection, data coding, data analysis and reporting. Using a thematic analysis process at each site the data were coded inductively with a thematic coding scheme. Then a collective and collaborative process was used where the researchers identified and defined themes across all the data. As the combined themes and concepts emerged, further data reduction and interpretation occurred. This culminated in a novel, systematic and innovative group analysis and writing process. The PAR framework allowed Aboriginal and Torres Strait Islander researchers to become equal and valued members of the research team. Despite numeracy and literacy levels, the Aboriginal and Torres Strait Islander researchers were well supported in their capacity development. Two major challenges occurred, one during data collection and the other during analysis. During interviews, community-based researchers initially did not probe participants for further



information on areas of common understanding. During analysis the other challenge was deciding on how to document community-based strategies that were deemed ineffective (on the basis of evidence) in reducing transmission of influenza but were perceived effective by the community.

Research action and feedback

The participants spoke of the need to enter into a respectful dialogue with Aboriginal and Torres Strait Islander communities, to discover what communities wanted to know before authorities told them their views. It was considered important that researchers, government agencies and health services listen deeply to what is really meant, and then share the information that is needed by the communities.

An interim report was developed and presented to participants and organisations involved in the study to closely consider and comment on what was found as an essential activity of the PAR framework³⁴. The data gathering process and the dissemination of the interim report provided many opportunities for the PAR process to flow from the research. New or modified ways to reduce risk from H1N109 were adopted by families, health services, community groups and government departments involved in the research. Examples included families increasing hand washing and reducing direct social contact when sick, a childcare centre ensuring that sick children did not attend the centre, health services planning for outreach services and a state health department engaging more closely with the Aboriginal community-controlled health sector. Self-determination and empowerment are key values that the research action and feedback was able to support. These values are integral in the development of Indigenous health. The major themes and subthemes from the study (Table 1) were confirmed throughout the PAR framework.

Discussion

Vulnerable or neglected groups and populations often become more disadvantaged during epidemics and other emergencies³⁵. Typically their special needs are ignored because health system

responses are designed to maximise efficiency and produce the best outcomes for the majority of the population³⁶. The research framework that was adopted allowed the voices of vulnerable groups to be heard, listened to and appropriate action taken in respectful, collaborative partnerships. The most effective responses in this study were seen in relationships that had been established over decades between Aboriginal medical services and investigators, while research relationships established specifically for the purposes of the project were less successful because of changes in personnel.

A number of strengths of the research framework used became clear throughout the project. The perspectives of Aboriginal and Torres Strait Islander people were paramount to the research process. Respect of and for Aboriginal and Torres Strait Islander cultures underpinned the project. PAR is an approach that may work towards de-colonising research^{27,28,37} and bringing about sustainable change. Further strengths of PAR included having people working together with different capabilities and skills but complementary experiences and directions, research training, mentoring and capacity building of the whole team, and actions to reduce the risk of H1N109 being implemented as the research progressed.

In this study, the PAR framework enabled a collaborative partnership between Aboriginal and Torres Strait Islander community members, organisations, and novice and experienced researchers. The collection and analysis of this data formed an interim report that captured the main findings so that health services and organisations could use this to improve their responses to pandemic influenza. Throughout the entire project, Aboriginal and Torres Strait Islander community research assistants were actively involved in research capacity training, data collection, group analysis of the data, and writing up of the research findings. The important role they played in the research project has been described previously¹⁷. The findings from this research were used as an advocacy tool with government to include Aboriginal and Torres Strait Islander peoples in the National Pandemic Plan. This is a good example of how knowledge translation could look in practice.



Table 1: Major study themes and subthemes

Major theme	Subthemes
Importance of family and ways of life	Keeping families safe Our families, our ways
Realities of living	Big families, small houses Realities of inadequate infrastructure
Key messages for government and health services	Knowledge is power Ask us, listen to us, share with us Partnerships and collaborations are vital More responsive health services are needed Acceptable strategies

Making the implicit explicit was both a strength and a challenge for the research team. At times, the Aboriginal and Torres Strait Islander researchers were placed at some risk when they explored issues that most often go unsaid in communities. As a result, when working with the data, the community researchers were able to provide a more complete translation of the concepts raised by the research.

If the project was to be repeated, the research team would be expanded to include a person allocated to coordinate community engagement at each site. Further, to enable deeper understandings to emerge and acceptance of new measures developed, all participants and groups would need to be fully engaged in the research process. Community organisations operate in dynamic and changing environments, therefore flexible engagement strategies are necessary. Developing strong mutually agreed frameworks for engagement may assist in this challenging process.

The initial results of this research have been published elsewhere and include a number of recommendations and strategies for government, health services and families¹. An important focus of this article is the translational research framework³⁸. Translational research contributes to informing practice and policy in Indigenous health³⁸. Translational research is associated with the concept of knowledge translation developed in Canada and mandated by the Canadian Institutes of Health Research (CIHR)^{38,39}. Within CIHR's 'knowledge to action process' model, a representation of knowledge translation, this article can be

defined as the 'identify problem/identify, review and select knowledge' step^{39,40}.

Actions to reduce the risk of pandemic influenza transmission in the community need to be driven by the understandings emerging from this research. The importance of family and community ways was a strong and recurring message for governments. The reality of life in Aboriginal and Torres Strait Islander communities differs from that of many non-Indigenous communities, and pandemic influenza strategies need to take account of these differences. The key messages to government and health services stemming from the research were that community engagement and partnership is vital, and health services need to be more responsive. In 2013, this study's research team was given the opportunity to provide feedback on the revised Australian Health Management Plan for Pandemic Influenza. The results of this research are being incorporated into the latest revisions of this plan.

The social aspects of communities, such as cultural values, importance of norms, strong family ties, and social networks, need to be integral in research methods for addressing issues in vulnerable populations. The model of research described here could provide a useful starting point for researchers who are working in these environments and with these populations, and argues for respectful engagement with communities as a cornerstone for this type of research.



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