REFLECTION

View From the Canoe: Co-Designing Research Pacific Style

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ABSTRACT

In 2016, Rose Lamont and Tana Fishman were the first patient-clinician dyad from outside North America to attend the North American Primary Care Research Group (NAPCRG) Patient and Clinician Engagement Program workshop. They returned to New Zealand inspired and formed the Pacific People's Health Advisory Group and a Pacific practice-based research network (PBRN). They are guided by the principles of co-design, and the Samoan research framework fa'afaletui, which emphasizes a collective approach and importance of reciprocity and relationships. Their collective inquiry aims to reduce health inequalities experienced by Pacific people in South Auckland. Their community group members and PBRN are generating research questions being answered by university-based graduate students. When they embarked, they knew not the direction in which they headed. With guidance, their community members and clinicians have led the way. By giving everyone a say in where they are going and how they get there, they are modeling what they wish to achieve—an egalitarian approach which decreases disparities for Pacific people.

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The North American Primary Care Research Group (NAPCRG) implemented the Patient and Clinician Engagement Program (PaCE) in 2013. This program trains "dyads" of patients and primary care clinicians to understand and engage in primary care research.[1] The overarching premise is that community engagement in research is necessary for evidence to be translated into best practice to improve health and well-being—the principle of co-design.

In 2016, Felicity Goodyear-Smith, a professor in family medicine from New Zealand, asked a family physician colleague, Dr Tana Fishman, if she would like to attend PaCE along with a patient, as the first "non–North American" dyad. Tana agreed and invited Ms Rose Lamont, a Samoan teacher from South Auckland. Rose and Tana attended the training and the subsequent NAPCRG conference in November 2016. Not knowing what to expect, they approached the PaCE workshop with some trepidation, but soon found themselves enthusiastically engaged. They learned how to read poster presentations and critique them from a patient's perspective, and the importance of engaging patients in the research process from the outset. Other PaCE members described how patient groups in their own communities met to develop research agendas in partnership with university-based researchers.

Being together for a week meant that Tana and Rose shared details of their personal lives with each other. You can read the story about this doctor and patient traveling together in our previous publication.[2] Rose is a teacher and worried that she had nothing to contribute to a medical conference. Having developed this relationship with Tana meant that Rose could ask her to explain whenever she did not understand. In Pacific cultures deference is given to those in positions of authority or in highstatus roles such as doctors, and asking them questions is considered disrespectful. The development of an egalitarian relationship between this Pacific patient and her family physician broke new ground, and they later recognized that without this, their involvement would not have been successful.

Rose and Tana returned to New Zealand inspired. Over the next year, Rose recruited a group of Pacific Island community members, and formed the Pacific People's Health Advisory Group (PPHAG). Members were invited from personal and professional networks, reflecting the core values of connectiveness and relationships in Pacific cultures. This differs from other consumer groups that recruit using criteria such as qualifications and experience and interviews. Group members belong to a number of Pacific ethnicities, come from a variety of backgrounds, and range from young people to the retired.

Pacific people have migrated from island nations such as Samoa, Tonga, Cook Islands, and Niue, and form the majority of the South Auckland population. In general, Pacific people live in high deprivation and experience poorer health outcomes than the general New Zealand population.[3] The aim of PPHAG is to identify where research is most needed to help improve the health of Pacific people in South Auckland. Each member has developed research questions on areas they think are important to answer, such as youth mental health, care of the elderly, diabetes, gout, teenage pregnancy, rheumatic fever, and impetigo.

In New Zealand, all family practices belong to a Primary Health Organization network (PHO).[4] Pacific practices in South Auckland predominantly belong to a Pacific-led PHO called Alliance Health Plus trust. Through their clinical director, Tana, and their nurse leader, Ms Pauline Fuimaono Sanders, the PHO generously offers support to PPHAG. The PHO provides a venue, meal, and stipend for those who attend the evening meetings.

PPHAG members discussed their areas of possible research interest over the next few months, but at that point the process stalled. Then Felicity invited a Tongan researcher, Dr Malakai 'Ofanoa, to join with her, and together they ran a workshop for the group to give them a basic understanding of research principles and Pacific research methodologies. This included explanations of the differences between quantitative and qualitative methods, and how to ask research questions.

Co-design and action research were explained—where research is actively done by, with, and for the stakeholders who will benefit from it, such as patients, community members, and clinicians, rather than done on them.[5] Participatory action research is a team approach. Endusers can generate the questions, help in the study design, and be involved in its implementation. They can also assist in evaluation of its outcomes. Co-design means that the stakeholders have ownership of the studies, use the findings, and help in dissemination. Implementing change in response to new information requires enthusiastic champions, and there are none better than those involved in its creation.

The Pacific research paradigm fa'afaletui was introduced–the way (*fa'a*) the stories from different groups or "houses" (*fale*) are woven together (*tui*). This is a Samoan framework with an emphasis on a collective approach, working together–on reciprocity and relationships. It fits well within the co-design model and suits a mixed methods approach. For the fa'afaletui approach, 3 perspectives are all required for action in order to solve a problem.

The first perspective is from the top of the mountain. From here, you can look over the entire landscape and bring a long-distance lens to the problem, see the big picture. This may be a quantitative approach, looking at national or regional statistics. The second perspective is the view from the top of the tree. This brings a middle-distance lens to the issue. Data from particular communities or populations may be collected and analyzed. Lastly, there is the perspective of the person in the canoe fishing. People closest to the "school of fish" are most affected by the problem, they know the small details. However, they do not necessarily have the broader view that allows them to account for all the issues contributing to a problem. We need to hear their voices, give them the opportunity to tell their stories. This fits well with qualitative methodology.

Another associated Pacific concept is fonofale. This uses the meeting (*fono*) house (*fale*) as a metaphor for holistic health and well-being, describing the family as the foundation, and the 4 house-posts (spiritual, physical, mental, and social) supporting a roof of cultural values, set in a wider context of time and place. Fa'afaletui and fonofale are perspectives that relate to the social ecological framework, which models interconnected circles around an individual of microsystem (family), mesosystem (social institutions), exosystem (community), and macrosystem (cultural values and societal policy).[6]

Following the research presentation, members worked in small groups to explore how their research questions might be framed in a way that they are able to be answered, can lead to new knowledge, and have results that might make a difference.

Family practices in South Auckland were then invited to join PPHAG as partners in research. Members of the PPHAG are enrolled patients with some of these practices. Through the PHO, each practice was asked to designate 1 staff member as a research officer. This could be a family doctor, practice nurse, or practice manager. These are the champions of research for their respective practices.

A Pacific practice-based research network (PBRN) was established to conduct studies in community settings and connect PHHAG and university researchers with clinicians caring for Pacific people in the community.[7,8] Having a PBRN has provided a framework to enable patients and clinicians to generate questions relevant to their own communities, and then assist in these being answered. PPHAG provides an authentic voice on problems facing their own community.

At a meeting attended by PPHAG members, the practice research officers, university researchers, a major funder for Pacific research, and key Alliance Health Plus PHO staff, the PBRN was established. Felicity and Malaki provided further training on how to ask meaningful research questions.

Following the meeting, the community members and the practices produced priority research questions from their areas of interest. Felicity and Malakai collated these to see which were true knowledge gaps, were doable, and where the answer might lead to important health differences. One question met these criteria, and also was asked by both community and practice members, so we selected this as the first project. This question is "How can we make it easier for our Pacific people to access and take medication to prevent gout?" Gout is debilitating and painful, leading to time off work and interfering with family life, plus other serious sequelae. Pacific people have a very high prevalence of gout (6.5% women and 22% men aged over 20 years),[9] and are also less likely than non-Pacific to take urate-lowering medication to prevent acute attacks of gout.[10] This is despite a number of gout management initiatives that have been introduced to increase the use of preventative medication.

We are using graduate students (honors, masters, doctoral) to address the issue, using the fa'afaletui approach. Questions to answer include "How big is the problem?", "What has already been tried?", and "What do the people think?". An honors student is looking at national and regional statistics, and triangulating these with our PBRN clinical data, on the prevalence of gout in Pacific and non-Pacific people, the proportion of gout patients who have had their blood urate levels measured, been prescribed urate-lowering drugs, and have had these dispensed regularly. She is looking at trends over time, to see if there is any indication that a local initiative appears to have made any difference.

A masters student has conducted a literature review on international gout prevention initiatives, and taking stock of all New Zealand gout programs, including educational campaigns, nurse-led programs, and pharmacist-led initiatives.

The New Zealand Health Research Council has dedicated funding for projects that create Pacific health knowledge, help translate the findings into benefits in Pacific health, and hence enhance Pacific health and well-being. They also wish to build capacity and capability of the Pacific health research workforce. Our project meets all these objectives. Felicity and Malakai have made a grant application, which includes a PhD scholarship for a Pacific student. The project will build on the knowledge gained by our masters and honors students. Community members, gout patients, and clinicians will be asked to brainstorm ideas about what else might work to engage Pacific patients with gout, and help them take preventive medication regularly. They will be encouraged to think laterally and explore culturally effective means to connect with their people. This will lead to the development and evaluation of an intervention.

It is time to grow our research capacity. PPHAG and the PBRN have many more questions they would like answered. We now have planned a further meeting where we will invite a number of Pacific researchers from both our university and other institutions. We wish to foster alliances and relationships between our Pacific community, family practices and other researchers, to see if they would like to get involved, and use their own graduate students to pick up and address other research areas identified as needing evidence to effect change.

Upon reflection, when we embarked upon this journey, we had little idea of the direction in which we were headed. With guidance, the process has enabled our community members and our clinicians to lead the way. By giving everyone a say in where we are going and how we get there, we are modeling what we wish to achieve–an egalitarian approach which decreases health disparities for Pacific people.

As one PPHAG member, a retired community worker, says, "For the first time I have equal power as a consumer. I have the freedom to say what I think, and what I need for my people."

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Key words: community-based participatory research; Pacific people; co-design; practice-based research network; New Zealand; patient and clinician engagement; primary care

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