

Travelling companions: a story told by a patient and her doctor

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The Patient and Clinician Engagement (PaCE) project¹ involves collaborative dyads of North American patients and their family physicians / general practitioners working with university academics on participatory research projects to reduce disparities and improve community-based health outcomes.² PaCE dyads meet annually at the North American Primary Care Research Group (NAPCRG) conference.

Felicity: In my role as NAPCRG International Committee Chair, and department head of general practice, University of Auckland, I initiated the first non-North American PaCE dyad. I approached colleague Dr Tana Fishman, who in turn invited Rose Lamont, a patient of Pacific decent with whom she had a long-established doctor-patient relationship, to form their dyad. In November 2016 they travelled to the PaCE meeting at NAPCRG. This paper describes their journey and its implications with respect to maintenance of the professional relationship between doctors and their patients.

Tana: Travelling to the airport to meet Rose was very unusual. It was difficult to explain to colleagues and friends that I was travelling with my patient. I worried about maintaining professional boundaries³ and appropriate self-disclosure;⁴ behaviours I had incorporated into my general practice for years. I was cautious. I did not consider Rose a friend, and had no connected associations with her. Why I chose her I still understand poorly, except that I knew she was intelligent, caring and grounded.

I was acutely aware to ensure Rose felt safe and was an equal partner in our decision-making. Rose, an intermediate school teacher with a master's degree in education, was born in South

Auckland to native-born Samoan parents. In Samoan culture, respect for parents, elders, chiefs, ministers and doctors is woven within the fabric of society and posed a possible power imbalance issue. This cultural understanding is practiced abroad wherever Samoan people reside. Patients respectfully follow the recommendations of doctors without question. This contrasts dramatically with the philosophy of PaCE, where patients and doctors share an equal partnership.

My role was to help Rose make sense of the medical and research aspects of the conference and answer questions. Her unique approach to health seen through a school teacher's lens attracted interest from other dyads. It was clear that Rose held enormous knowledge about her Pacific people and the socioeconomic determinants of health.

Travelling together included sharing meals, exercise opportunities, tourist attractions, group discussions, costs, our opinions and our personal lives. This unique and intense sharing resulted in a partnership with equality of power and decision-making. The boundaries of our patient/clinician relationship clearly shifted.

Rose: I was very hesitant when considering my participation in this project. I am a school teacher, how can I contribute to anything medical? I was worried about being called on for an opinion and not knowing what to say unless it related to education. I felt nervous travelling to the airport as I did not understand what I was going to, but excited to be the first New Zealand patient involved in such a project.

I had known Tana many years professionally but not personally. Meeting up at the airport, I felt comfortable to be travelling with her. She was easy-going. Initially the PaCE meeting was overwhelming, I felt lost. I had trouble grasping what it was all about. It seemed everyone else knew each other. Tana looked after me. I asked many questions to help understand both the medical and the research world I found myself in. As I met other dyads, sometimes I could not immediately tell which was doctor and which patient. I found their stories inspirational.

If Tana had maintained her professional distance, I would not have been comfortable, and the experience would not have been so valuable. Because we had shared about our families and our personal lives, I was able to be honest whenever I did not understand and ask questions. In a professional setting, it would not have been ok for me to ask.

During the conference I engaged in robust discussions about health care delivery, and began to learn the basic tenets of primary care research. In my role as a school teacher I have seen first-hand the health inequities of the Pacific population in South Auckland. This seemed like a way to do something about this.

Felicity: Rose and Tana returned to New Zealand inspired. They focused on the health disparities of South Auckland, an area associated with deprivation, crime and violence, but also cosmopolitan with a thriving multi-ethnic culture and a centre of hip hop. It became their joint mission to make a difference in their shared communities of engagement.

Rose has recruited a Pacific Peoples Health Advisory Group (PPHAG) which includes school teachers, university students, a credit union manager, and social workers. In association with a Pacific-led Primary Health Organisation they plan a 'fono' (assembly) to meet with primary health researchers as future partners for community-based research.

PPHAG members acknowledge their 'consumer designation' but want an active voice and shared decision-making, a shift away from representation. This PaCE project will propel the Pacific voice away from the 'consumerism model' into to one of equal voice and power.

PPHAG members recognise this irony for the typically passive Pacific cultural norms for patients with doctors. The shift in doctor/patient boundaries may also be early steps for the future of improved health care delivery models. The journey continues.

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Declaration of interest Statement

No author has any conflict of interest to declare.

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Tables and Figures Nil