

## Travelling companions:

a story told by a patient and her doctor

### BACKGROUND

The Patient and Clinician Engagement (PaCE) project<sup>1</sup> involves collaborative dyads of North American patients and their family physicians/GPs working with university academics on participatory research projects to reduce disparities and improve community-based health outcomes.<sup>2</sup> 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 my colleague Dr Tana Fishman, who in turn invited Rose Lamont, a patient of Pacific descent 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 article describes their journey and its implications with respect to professional boundaries between doctors and their patients.

### MEETING UP

*Tana:* Travelling to the airport to meet Rose felt very unusual. It was difficult explaining to colleagues and friends that I was travelling with my patient. I worried about maintaining professional boundaries and appropriate self-disclosure,<sup>3</sup> 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 that 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 practised abroad wherever Samoan people reside and 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 the Pacific community 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 resulted in a partnership with equality of power and decision making, and 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 but also 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 easygoing. Initially the PaCE meeting was overwhelming and I felt lost. I had trouble grasping what it was all about and it seemed everyone else knew each other. Tana looked after me. As I met other dyads, I sometimes couldn't immediately tell who was the doctor and who was the 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 to ask questions. During the conference I engaged in robust discussions about healthcare 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 very 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.

### AND NOW

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 that they are a consumer group but want an active voice and shared decision making; a shift away from representation. This PaCE project will propel the Pacific people from being passive recipients of health care to having equal voice and power. This shift in doctor-patient boundaries may also be early steps for the future of improved healthcare delivery models. The journey continues.

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