The fork in the road: Exploring factors which influence whether Aboriginal and Torres Strait Islander peoples living with chronic disease remain engaged with health services

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The Kanyini Qualitative Study

The Kanyini Vascular Collaboration (KVC) was established by Aboriginal and Torres Strait Islander as well as non-Indigenous health researchers, policy advisors, health economists, clinicians and health service partners with the aim of improving health outcomes for Aboriginal and Torres Strait Islander peoples (www.kvc.org.au). The Kanyini Qualitative Study (KQS) is the second project in a series of discrete yet inter-related studies conducted by KVC with Aboriginal and Torres Strait Islander communities and primary health care partners in New South Wales, Western Australia, South Australia, Queensland and the Northern Territory. In particular, the KQS was designed to explore principle barriers to and enablers of quality chronic disease care, in order to inform an understanding of what better systems of primary healthcare might look like for Aboriginal and Torres Strait Islander populations. This monograph, the second of a series being developed by the KVC, presents and discusses the findings as they relate to Aboriginal and Torres Strait Islander peoples remaining engaged with healthcare services for chronic disease.

Introduction

Chronic disease is, by definition, a long-term and perhaps permanent state in a person's life. The experience of chronic disease involves illnesses that rarely resolve spontaneously [1]. Its onset can signal an assault on a person's physical self and their sense of identity and self-worth [2, 3]. Care that improves the health of people with chronic disease requires long-term strategies that promote and sustain patients' engagement with healthcare services. However, sustained engagement with health services by Aboriginal and Torres Strait Islander peoples is often far less than what would be expected, given the burden that chronic disease imposes [4].

The notion of patient engagement has risen to prominence over the last decade as health care has undergone a transition towards patients becoming engaged in care, rather than being merely passive recipients [5]. In the American healthcare sector, patient engagement has been termed "the blockbuster drug of the century….[with] ….the potential to transform the practice of medicine" [6, p. 357]. The engagement process is based on the premise that the patient has the ability to balance clinical information and professional advice alongside their own needs and preferences, resulting in a trusting relationship which benefits the experience of the user [7].

The term 'engagement' has also been used interchangeably with other similar concepts including patient-centred health care [8] and patient activation [9]. Definitions for engagement typically encompass aspects of care, such as meeting the patient's needs, wants and expectations in relation to healthcare; the need to share involvement in decision making between patients and providers; and the need for an appreciation of the patient's context [10]. Engaging patients more fully in their care has been shown to improve patient experience and perceived quality of care, to encourage healthy behaviour, to reduce errors and to ultimately lead to improved health outcomes [5]. Patient-centred care has also been found to result in patients who are more likely to trust their clinicians and adhere to recommended treatment and also who are less likely to die following a major event such as acute myocardial infarction [11].

A relationship between 'patient-centredness' and improved health outcomes derives, at least in part, from the fact that patients and families bring useful knowledge to care encounters "if they are invited to do so" [12, p. 559]. The development of interventions to improve health literacy, patient-provider communication, shared decision-making and patient self-management emphasises a respect for patient autonomy and recognition of the patient's unique position to improve the effectiveness of their care. Not surprisingly, these initiatives have gained traction internationally, with patient engagement now seen as a critical component of a high-performance healthcare system [5].

Although previous research has explored the interaction between patient experiences of care and clinical outcomes within the primary care sector, there are little data to assist practitioners to better understand the nature of these interactions in the more complex setting of chronic disease care and management [13]. By identifying the key mechanisms operating in the space between Aboriginal and Torres Strait Islander peoples living with chronic disease and 'the system,' we can better understand what is happening during engagement, as well as 'how' and 'why' people choose to remain with, or disengage from care. In particular, identifying these mechanisms will give us a better understanding of what works better, for whom, in what circumstances and why [14]. This monograph focuses

specifically on features of patient/provider/system interactions that influence the nature and longevity of engagement of Aboriginal and Torres Strait Islander peoples with chronic disease care.

The KQS Monograph Series

This monograph is the second of five which aim to explore aspects of care and well-being for Aboriginal and Torres Strait Islander peoples living with chronic disease. The following monographs are also included in this series:

- Monograph One: Why Aboriginal and Torres Strait Islander peoples seek care;
- Monograph Three: How participants understand care and the caring relationship;
- Monograph Four: How health systems influence the way in which people engage with or remain engaged with healthcare; and
- Monograph Five: How wellness and well-being is framed, from the perspective of Aboriginal and Torres Strait Islander peoples living with chronic disease.

Method

The KQS was designed to address the following research questions:

1. What frames Aboriginal and/or Torres Strait Islander Australians' engagement with care?

2. What does it mean to be looked after properly?

3. What are Aboriginal and/or Torres Strait Islander Australians' experiences of care for chronic disease?

4. What are the primary barriers to and enablers of care for Aboriginal and/or Torres Strait Islander Australians with chronic disease and their families?

5. How do we develop better systems of care for Aboriginal and/or Torres Strait Islander Australians?

The methods for this study have been described previously (see Monograph 1). In brief, from July 2008 to February 2010, we conducted semi-structured interviews with 223 participants (Table 1), 126 of whom were Aboriginal and/or Torres Strait Islander peoples with and without chronic disease (Table 2), and 97 of whom were Aboriginal and Torres Strait Islander or non-Indigenous healthcare providers (Table 3), healthcare service management or administrative staff.

Table 1: Study Participants

	Aboriginal and Torres Strait Islander Participants (n=126)	Healthcare Provider Participants (n= 97)	Total Participants (n=223)
- Female	71 (56%)	62 (64%)	133 (60%)
- Male	55 (44%)	35 (36%)	90 (40%)
- Urban	43 (34%)	30 (31%)	73 (33 %)
- Regional	27 (21%)	38 (39%)	65 (29%)
- Remote/Very Remote	56 (45%)	29 (30%)	85 (38%)

Table 2: Summary of Aboriginal and Torres Strait Islander community participant characteristics

Participant Group 1: 'Community participants'*	No.	Regular Client	Irregular Client
Urb 1 (Queensland)	27	22 (17%)	5 (4%
Urb 2 (New South Wales)**	16	11 (9%)	2 (1.5%)
Reg 1 (Queensland)	16	9 (7%)	7 (5.5%)
Reg 2 (New South Wales)	11	11 (9%)	0 (0%)
Rem 1 (Central Australia)	17	11 (9%)	6 (5%)
Rem 2 (CA)	6	4 (3%)	2 (1.5)
VRem 1 (CA)	14	14 (11%)	0
VRem 2 (CA)	16	16 (12%)	0
VRem 3 (CA)	3	3 (2%)	0
TOTAL	**126**	**101 (80%)**	**22 (17.5%)***

*Abbreviations are explained in Table 4, below.

**The remaining 3 community participants included 1 family member and service utilisation data were missing for 2 participants.

Table 3: Summary of healthcare provider participant characteristics

Participant Group 2: 'Healthcare providers'	No.	Aboriginal Identity		Type of Healthcare Service		
		ATSI*	Non-ATSI*	ACCHO**	Gov^	NGO^^/ Private Sector
Healthcare providers						
Aboriginal Health Worker	17	17	-	16	1	-
Nurse	29	4	25	13	14	2
Doctor	10	-	10	8	1	1
Allied Health	6	1	5	5	1	-
Registered Nurse manager	4	1	3	2	2	-
General Practitioner manager	6	2	4	4	2	-
Aboriginal Healthcare Worker manager	3	3	-	1	2	-
Non-clinical manager	5	3	2	3	2	-
Board member	2	2	-	2	-	-
Chief Executive Officer	4	3	1	4	-	-
Administrative staff (receptionist; driver, etc.)	9	7	2	6	3	-
Key informant	2	-	2	-	-	2
TOTAL	**97**	**43**	**54**	**64**	**28**	**5**

* Aboriginal and Torres Strait Islander
** Aboriginal Community Controlled Organisations
^ Government
^^ Non-Government Organisation

Data were analysed thematically and the themes which inform the reasons **why Aboriginal and Torres Strait Islander peoples remain engaged with or disengage from care** are presented and discussed below. In order to contextualise and signify key participant characteristics, codes (Table 4) are presented at the end of each quote.

Table 4: Participant Coding

Ethnicity	Aboriginal and/or Torres Strait Islander = Aboriginal Non-Indigenous = Non-Indigenous
Role	Community participant = Community Administrative Staff = Administrative Health Practitioner = Practitioner Health Service Management (includes board members and chief executive officers) = Manager Key Informant = Key Informant
Gender	Female = F Male = M
Location	Urban site = Urb Regional site = Reg Remote site = Rem Very remote site = VRem

Results

Our analysis revealed three major themes impacting Aboriginal and Torres Strait Islander peoples' sustained engagement with care for chronic disease. The themes were motivators and enablers; tipping points along the care continuum; and navigating care on one's own terms, including resisting engagement and 'pushing back' against the system.

Motivators and Enablers

A number of factors motivated and/or enabled Aboriginal and Torres Strait Islander community participants to maintain engagement with health care services over time. There were often acute events, such as a heart attack, which could be key to ongoing engagement. Although such an event frequently took people by surprise, it also brought individuals into contact with health care services, which in turn presented a chance to review past decisions and contemplate behaviour change. Acute events often brought patients to a place where they were faced with deciding whether or not to seek the support of health services in order to address their health concerns over both the short and longer term. Patients' families also acted as a critical motivator for engaging with health services. Their concern and worry encouraged patients to engage with health services and played a role in 'keeping them honest' during care encounters. Finally, we found that healthcare practitioners' investment in the *process* of engagement impacted on *outcomes* of engagement. Practitioners' communication skills, as well as their ability to establish trusting relationships and maintain connections with patients over time were associated with sustained engagement.

Coming to a Fork in the Road

Aboriginal and Torres Strait Islander community participants often described engaging with healthcare services after acute events like a heart attack. Some were motivated to engage when others in their family or community experienced a life-threatening episode.

> *[When a bloke I played touch football with] had the heart attack it really made me sit up and think...we took it for granted, our health. We thought we were immortal. We could just live forever. But when he had the heart attack...I went and got checked up...But you know, that was one story where what happened to them changed a lot of the way people thought...Now men are starting to see well, you know, you need to look after it [your health]... [Aboriginal_Community_M_Urb]*

For community participants leading busy lives with multiple competing priorities, attention to healthcare had not been a major focus until the seriousness of their condition became undeniable.

> *Yeah, that was me exactly before, I was exactly like that [finding it hard to maintain motivation to stay healthy]. I'd walk every now and again, but it's not until something drastic or dramatic happens to you and then it makes you reassess your life and then you can see the path you were going down. Like when you are sitting in a bed and you have got three or four doctors doing different things…that's an eye opener, you know. I thought, "Oh, shit I was doing something wrong". [Aboriginal_Community_M_Reg]*

Several health practitioner participants also observed behaviour change among their clientele. Some attributed this to an increasing awareness of the impact of chronic disease on their families and community, especially when *"[t]hey can see there're a lot of people that are dying young around them." [Aboriginal_Practitioner_F_Reg].* Other practitioners spoke of patient success stories after engaging with care, including an increased adherence to necessary medications, increased physical activity, and improved quality of life. Practitioners confirmed the community perspective that a life-threatening event frequently proved the catalyst to engaging with care over time.

> *One of those guys…he's just such a great success story in that…I mean it's terrible he had his big scare and went into hospital and nearly died, but he's quit smoking and he's just taken his life into his hands as a result, and he's so happy...And it's really lovely to see him thriving. [Non-Indigenous_Practitioner_F_Reg]*

Indeed, for some community participants, acute, traumatic events proved to be turning points in their lives. One community participant spoke of reassessing his life after a sudden heart attack, and described sustained engagement with healthcare providers which in turn helped him manage his underlying diabetes.

> *No I didn't [have a regular doctor]. You know what black guys are like, they don't like seeing doctors...Yeah [since my heart attack] I see the doctor quite regularly...it makes me feel good every time I go around and see the doctor, and [he] checks all my weight and everything and my size around the waist and it's all coming down, so that's good...so I was sort of getting in tune with my body, you know and, well I think I am. [Aboriginal_Community_M_Reg]*

The Role and Influence of Family

Aboriginal and Torres Strait Islander patients' families emerged as a prominent influence as to whether or not people engaged with chronic disease care. For some, family also proved critical to recovery from a life-threatening event.

> *[Family and friends'] help was very important to my recovery and it makes a big difference when the family is there to help you…I don't think I would probably be here today or be involved in the work I am doing if it wasn't for them…Just being there for you. Visiting you in hospital. Giving me space and time to adjust. Being there to talk about, being a shoulder to lean on and providing space to get away from what had just happened to me. [Aboriginal_Community_M_Reg]*

A number of community participants identified that "[t]*he important focus in my life has been my kids." [Aboriginal_Community_F_Reg]*, and spoke of how their desire to 'be there' for their children and grandchildren motivated them to live a healthier life.

> *...[my wife's] family is her life, that's what keeps her breathing right, the grandchildren, the great grandchildren and that's what keeps us basically going. If they weren't there, kiss your arse goodbye...I had to be the strength for the family because I'm the oldest, you've got to be strong, you cannot let yourself down because if I let myself down, that means my grandkids are going to go down, their parents are going to go down, I've got to be strong irrespective of what happens. [Aboriginal_Community_M_Urb]*

Importantly, both patients and providers observed the critical role that family could play in keeping people honest during chronic disease consultations with practitioners.

> *Yeah, she [my wife] makes sure I don't go there [doctor's appointment] and tell a lie and things. And let the doctor know actually what happened there. Sometimes I veer off and I tell him something else. And she'll say, "No, no, no, it's not right", she'll say. No, she's there to check me all the time. [Aboriginal_Community_M_Urb]*

The Role of Healthcare Providers

Communication between Aboriginal and Torres Strait Islander community participants and their care providers was critical to sustained engagement. Community participants emphasised achieving understanding within care encounters.

> *I think a good doctor and a good nurse is someone that actually talks to you and not talk at you...not just babble on and keep talking and you don't have a clue and they're not going to stop and help you understand. [Aboriginal_Community_F_Rem]*

However, understanding was not always achieved. There was the potential for patients to receive mixed messages, especially if they had multiple care providers.

> *So the one doctor's saying [one] thing, another one's saying another thing, you know. And I'm in the middle of them, see, and I'm just popping them tablets. [Aboriginal_Community_F_Rem]*

Another community participant described a relationship with their doctor which enhanced communication and promoted sustained engagement.

> *They talk about that [meaning of blood results] all the time with me, the doctor. Every appointment I go to, she is telling me, "You shouldn't be doing this, you shouldn't be doing that and this is what you should be doing," and things like that. She talks all the time like that…Like she is like my friend to me. [Aboriginal_Community_F_Rem]*

Some practitioners described constantly working to improve their cross cultural communication skills because they knew how vital this was to improving engagement:

> *But how we transmit that information, making sure that we're actually being understood but also coming from their world view…how we use the metaphors and the analogies that we use to make it understandable and I think that's such an art, to making that really clear, concise and understandable, and appropriate. And I feel, for me, that it's an ongoing challenge in trying to improve how I deliver that information and knowing whether it's understood. [Non-Indigenous_Practitioner_F_Rem]*

Another important aspect of the role of the healthcare provider in influencing sustained engagement involved practitioners establishing trusting relationships with patients.

> *Well people start coming back to see you and you build up a following with patients and people start bringing relatives to see you or staff start bringing people in to see you and I think it was here about 18 months before that started happening… and that's not until people start coming in and thinking "Here's a guy who's listening to us, here's someone who's flexible who is not pushing medication at us or who is explaining things", that takes time to build up against that almost 200 years of lack of trust really. [Non-Indigenous_Manager_M_Urb]*

Factors key to making a difference to sustained engagement also involved practitioners' flexibility and perseverance in maintaining a connection with patients that endured over time. Importantly, these practitioners focused on getting "*enjoyment out of the relationship…you really want to take a motivational interviewing approach to it in a constructive way." [Non-Indigenous_Manager_M_Urb].* They approached each care encounter as an opportunity to help support behavior change, if not on that day, then at another time in the future.

> *Oh yeah, you do get victories. It's fantastic…Oh yeah, you do get lots of setbacks. You just have to let it go.…although you're not getting the immediate satisfaction you have to accept that you are making quite a big difference but there's no sort of immediacy to it…the most important thing is to maintain a rapport and remember that you're going to see them again. And you're going to see them again and again and again and that's what's important. [Non-Indigenous_Manager_M_Urb]*

Yet, at times, opportunities for making improvements in health outcomes were lost. When system constraints undermined practitioners' ability to engage properly with their patients, they were limited in their ability to respond fully to patients' needs, including helping to resolve ambivalence about managing their chronic condition:

There's a patient today, he comes in periodically every, I don't know, four weeks, for little things, but he's never taken his insulin, his blood sugar's always horrible, he never takes his anti-hypertensives. He never does anything. Yet he keeps re-presenting. So if we could just have some time with him...how about we go "Okay it's been four weeks since we've seen him, let's make that contact with him, let's see how…" you know? Cos I think he's right there on the verge of wanting to do it, he's just got to get over that hurdle, you know? But because we're so short of time, it's just this rush in, "What's your problem today? Right." and rush out. [Non-Indigenous_HP_F_Reg]

Tipping Points

A series of issues were identified where engagement became more challenging, or threatened to cease altogether. Experiences of racism, discrimination and distrust often resulted in patients disengaging from healthcare services altogether. Having to wait for care discouraged engagement when it was perceived by participants as indicators of system indifference to their needs, wants and expectations. Some participants struggled to adhere to necessary treatments, while others found that prioritising healthcare over other competing demands, including the needs of family, community affairs and cultural obligations, was challenging and frequently unachievable. We also found that there were significant social costs borne by individuals and communities when Aboriginal and Torres Strait Islander peoples needed to engage with care for managing their chronic disease. For many participants, these issues compounded, and resulted in patients disengaging, and walking away from care.

Racism, Discrimination and Distrust

The hospital environment was frequently associated with experiences of discrimination and racism. Hospitals in particular were associated with this type of treatment.

…there was one nurse used to be a bit cheeky....Talk down and all that, and there was, see when I'm feeling crook I get up and I go for a walk, you know. I get scared from, you know, when you're really crook you don't like to lay down and whatever. And...because I went for a walk downstairs and I came back up [I was told] I was using the hospital as a halfway house... it upset me, fair enough. And I got really crook then. That's not right. [Aboriginal_Community_M_Rem]

Patients and providers frequently dwelt on the emotional impact of these situations. Some patients described 'losing faith' in health services and people walking away from necessary care as a result.

I don't think the community have a lot of faith in mainstream, and I have to admit I've seen it where I've taken a client, or a couple of clients, to the hospital, and they're just treated atrociously. And I don't think it was because of their condition...It was because they identified as being Aboriginal…one of our clients was admitted because he had a heart attack, and she [one of our nurses] went in to visit him, and she could actually hear the nurses in the hallway speaking about him. And she walked out and she tore strips off them, because they were just so derogatory to him. And he ended up getting up and walking out. [Aboriginal_Manager_F_Urb]

Often trust between Aboriginal and Torres Strait Islander patients and practitioners did not come easily and providers had to *"work hard for it"* *[Aboriginal_Practitioner_F_Reg]*. Interruptions to

patient-provider relationships could manifest as a breach of this trust, which would have to be regained over time in order to re-establish engagement.

> *And one of the things I think was critical for me to understand in this is that, as workers, if we break our connection with people, we can go back to 'delicate' [engagement] from 'robust' very easily. That just because we think we've achieved a robust relationship, if we then disengage for any reason...then we actually go back to at least 'delicate'. We don't remain in the 'robust'. We've got to re-earn our 'robust' credentials...And I think that does show how profoundly underlying is the basic distrust, however much people may know that they have to rely on outside service providers in many ways. [Non-Indigenous_Practitioner_F_Rem]*

Waiting for Care

When primary healthcare services developed welcoming spaces for Aboriginal and/or Torres Strait Islander peoples and relationships between patients and providers were strong, waiting was rarely a problem. However, in other settings waiting for care was a regular and frustrating experience for community participants, especially when they had other commitments. This was a common driver of disengagement.

> *Well I come here and see the doctor a couple of months ago and they were just taking their time and I got the receptionist to ring them a couple of times and see how long they were going to be. And I waited and waited and it was about an hour past my appointment time and I got up and walked home. [Aboriginal_Community_M_Urb]*

A number of community participants perceived these delays as indicators of health system indifference to their presence, and that their needs were not as important as those of others. This often reinforced feelings of marginalisation and resulted in their walking away from care.

> *If you're sitting there waiting and just ask [the nurse] for a thing and then she disappears, goes away for a few - and never comes back...They tell you "We'll come back in a minute, just hold on there are other sick people in this hospital, you're not the only one". So you just wait...Then it makes you feel as if you're not there...you might as well just get up and go home and look after yourself. [Aboriginal_Community_F_Rem]*

Whether the wait was 'real' or 'perceived,' a number of health practitioners were attuned to the implications of patients having to wait to be seen, and understood how delays undermined people's motivation and capacity to remain engaged with care for chronic disease.

> *I guess people sitting out in the waiting room for an hour, two hour's wait. They start thinking 'Well why am I coming here for?' We need to provide a quality service that's not only sort of holistic but it also...it needs to run like a business, you need these people to come back. [Aboriginal_Manager_M_Urb]*

Sick of the 'Cure'

Aboriginal and Torres Strait Islander community participants often found that adhering to necessary chronic disease regimens and treatments was challenging. Participants highlighted the need to

commit to a strict schedule of medications. One remote-dwelling community participant's reference to a clinic staff member as *"that tablet sister" [Aboriginal_Community_F_VRem]* suggested how strongly some people associated medications with chronic disease care. Yet despite their importance, some patients lost motivation to continue with necessary drug therapies.

> *I'm diabetic. I give myself insulin. I give myself insulin in the mornings. Sometimes I don't do it. So I feel sick of it I suppose and don't want to do it anymore. [Aboriginal_Community_F_Rem]*

The level of effort required to participate regularly in chronic disease management was overwhelming for many, and contributed to disengagement.

> *And a lot of them I think are getting sick of diabetes, they are sick of hearing it cos we're giving it to them every three months and then you do your eye checks and do your doctor appointments...like we are expected to bring them in four times a year plus all the other checks for their eyes and feet. And like I said a lot of them get fed up with it and you just lose them. [Aboriginal_Practitioner_M_Reg]*

A number of practitioners understood and empathised with people who were struggling to remain engaged with treatment.

> *I mean, there's so many things happen here to people as patients that I would just go "Sod off, I'm not doing that!" So you know. Like a woman today, she said to me "I'm sick of taking all these tablets" and I said "Well that's totally up to you what tablets you take," you know? And it is. [Non-Indigenous_Manager_F_Reg]*

Competing Demands

Contemporary Aboriginal and Torres Strait Islander community life was frequently described by community participants and their care providers as a context where people needed to adapt their own priorities in response to daily demands from their immediate family, their broader social circle and community.

> *If health is high up on their priority list, instead of looking after their daughter or having to deal with domestic issues, then it's more likely that they can change their health as well. [Non-Indigenous_HP_M_Reg]*

Childrearing responsibilities and limited access to transport meant that having to first make and then attend a healthcare appointment was, for some, an almost impossible condition of engagement.

> *Because sometimes people miss out on their appointments because they don't have cars, they don't have money because they're all on welfare. And then there's a lot of children in the house, you've got to find a babysitter, you've got to take some kids with you, and there's a problem, and a lot of our people miss out on appointments that are very, very vital to their health issues. [Aboriginal_Community_F_Urb]*

Financial duress was another factor influencing patients' capacity to adhere to necessary medications. One elderly community participant spoke of the dilemma she endured when trying to prioritise food or medicine whilst living on a pension.

What they are doing now is that they are bringing a Webster pack out whether you pay or not, you know, but you are getting in debt…So it's hard for people, in sometimes, like if I can't get this bill down and that, I might not be able to afford to buy tablets. I'm telling you, I won't, because I have got to eat as well. I have got to pay my rent. [Aboriginal_Community_F_Reg]

Financial tensions such as this were not, however, a feature of interviews in remote areas where the section 100 scheme[1] ensures the supply of medications is free for Aboriginal and Torres Strait Islander peoples. However, in these regions other factors such as cultural obligations, including returning to one's country to attend ceremonial and cultural events, were issues which impacted on people's ability to maintain engagement with care.

…[W]hen I was on the on call list [at the renal unit] you would get called in quite frequently for your non-attendees...more the people who had gone away for like two weeks' worth of dialysis because they had something out bush that they had to go to. And that can be tricky too, people have cultural obligations that require them to travel very, very long distances...it makes it hard for them to stick to the treatment regime. [Non-Indigenous_Practitioner_F_Rem]

The Social Cost of Engagement

For those living in remote areas, adhering to required treatments often meant dislocation from one's country and limited ability to participate in cultural activities, family and community life. Many felt this to be a high price to pay for engaging with treatments even if they were able to prolong their life.

People get homesick when they go into town to stay on the [dialysis] machines. They miss their bush food, they miss everything. Even their family members, they've got to like be split apart... Some people I know from [community names withheld] they just gave up hope and just came back to the communities and just long stay with the families, they just passed away...They miss out on a lot. [Aboriginal_Community_M_VRem]

Communities were impacted by the loss of key members having to relocate to regional areas for medical treatment.

What is it to be a long way from somewhere?...So there's those sorts of costs...but what it really means in human terms for those individuals and what's left behind…and the roles of those people in the communities, that they're not there, the void, being the mediator…some of those older ladies, they're the bloody brains trust of [community name withheld] council, the native title units...those three out of 50 people that are the talkers and the insightful

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[1] To address identified barriers in accessing the PBS, special arrangements were introduced in 1999 for the supply of PBS medicines to clients of eligible remote area Aboriginal Health Services (AHSs). Under the provisions of section 100 of the National Health Act 1953, clients of approved remote area AHSs are able to receive medicines from the AHS, without the need for a normal PBS prescription form, and without charge. Clients of around 170 remote area AHSs, including Aboriginal community controlled AHSs and remote services operated by the States and Territories, benefit from improved PBS access through these arrangements [Australian Government Department of Health & Aging, 2010].

engagers are on dialysis now. When they were out in the Lands, that's who you were listening to. [Non-Indigenous_Practitioner_M_VRem]

When treatment became available closer to home engaging with care for chronic disease still came at considerable personal cost for some Aboriginal and Torres Strait Islander peoples.

I had one barrier when I was setting up [dialysis in community name withheld]. I got the lady to come up with me before we were going to place that demountable, where we were going to put it and she said "The Kadaitcha[2] man's there". I said "Okay". So I had to talk to everybody [in the healthcare organisation] and say "We can't put it there, we've got to put it somewhere else", and they just went "Oh, that's a load of crap, bullshit". So this poor lady sits in there, on her own, every day. She covers herself up and turns the lights off because she doesn't want anyone to know she's in there because she's worried about this thing and they wouldn't move the building for her. It's quite an unbelievable story isn't it? That someone else could turn around and say "Well that's a load of crap"…we could have found somewhere else. It was just that where we put it, it was close to the clinic so they didn't have to walk far if they needed to see them...They [Aboriginal patients] have to compromise with lots of things. [Non-Indigenous_Practitioner_F_Rem]

Navigating Care on One's Own Terms

A number of Aboriginal and Torres Strait Islander community participants appeared to resist Western notions of 'health' in favour of living life their way. At times, we identified attitudes of resistance and even 'pushing back' behaviours, against the healthcare system or individual providers. Although underpinned by the many challenges of living with chronic illness, perceptions of a lack of care, and personal control or influence when engaging with healthcare emerged as the key factors driving community participants' navigation of care on their own terms.

Resisting Engagement

Some community participants spoke of others who resisted engagement, appearing to prefer to live life on their own terms.

Because like, my mother was the perfect example of that. She dragged herself to death. She was literally smoking herself to death as well. And she didn't care. Because her mother done it. And then she said that she wanted to go out on her terms. And she wanted to live her life her way. So, some people, as much as you want to help them or tell them, they don't listen. [Aboriginal_Community_M_Urb]

Foregoing medication was a particular way some patients resisted engagement with chronic disease management. One community participant revealed, "*I have a cousin who's diabetic and, but he doesn't take his medication. And he should know that he needs to, but he doesn't. My grandfather doesn't. My uncle doesn't.*" [Aboriginal_Community_F_Reg].

Continuing medication also appeared counter-intuitive to some patients when they had come to feel well again.

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[2] Kadaitcha man – An Aboriginal sorcerer

I want them to take me off them tablets...because that is the first thing I said to Dr X. "I'm feeling alright now, this blood test you're taking now, I want you to take me off some of these medications." I don't really need it, you know, but am I demanding too much? [Aboriginal_Community_F_Rem]

Some practitioners shared insights into why patients may resist engaging with care.

Because people don't even, I think, see themselves as ill. Like it's chronic diabetes, and they're still being productive in [an Aboriginal] sense. They're still raising children, they're still being brothers and sisters and fathers and uncles and grandfathers. They're still going to ceremony. They're still hopping in cars…I think that there's probably a bit of people avoiding the situation, like they don't actually want to address it and engage with this sort of thing as 'illness.' [Non-Indigenous_Practitioner_M_VRem]

Patient attitudes of avoidance, seeming denial and/or non-adherence often perplexed and frustrated other health practitioners who were concerned that peoples' resistance to engagement frequently resulted in poor health outcomes.

…there's so much out there for the Indigenous people now towards health, but they just don't want to look after themselves. They know they've got diabetes, but they're still eating cake. They know they've got heart problems but they're still eating KFC. They know that. You know? [Aboriginal_Practitioner_F_Reg]

Pushing Back Against the System

Notably, as tensions between patients and health services increased, so too did the resolve of some patients to push the boundaries, often at risk to their own health, in order to navigate care on their terms. Practitioners in remote areas were particularly cognisant of these patterns, with one describing a patient who chose to not take medications in order to be evacuated out of their community for respite. In particular, the context of renal dialysis provided examples of people knowingly risking their health in order to make the system work for them.

See that's the only way us renal patients are able to go straight into Hospital is when we're going in an ambulance…That's what I growled on Monday, because I have to go in to thing [and the staff at the Renal Unit said] "Oh no you have to go to [the AMS] or go to A[ccident] and E[mergency] yourself." I said, "Well there's only [one] way that I'll be able to get access to that hospital without all this hassle is I'll stay home, I'll get crook, and they got no choice then but the ambulance to take me straight in and then I will get seen." [Aboriginal_Community_M_Rem]

Recurrent assaults on patients' agency and dignity compounded. As one health practitioner revealed, in these circumstances an interpersonal altercation could become the final straw, driving some patients to disengage and, in doing so, seriously risking their health.

Like one guy stopped going to dialysis because he was cranky at a nurse for not turning down the air-conditioning quick enough and he was cold, so he just stopped going to dialysis and was lying in his backyard...really short of breath and not able to get up.... And he was lying next to his mate who was angry...and also in the same state, like both of them just lying there in the backyard unable to get up, just massive oedema and clearly putting a

big load on their hearts that weren't very good anyway…but I think also there's this issue of punishing the service, that "These guys really want me to have it and if they don't treat me right I'm not going to do it"…and that decision to not dialyse is something that they can have control over…like "Okay I've got the decision to do this or not do this and if I'm unhappy I can…step off"…I see that with both men and women refusing dialysis because they're upset about something. [Non-Indigenous_Practitioner_M_Rem]

Critically, although they are, in principle, well-placed to do so, time-poor practitioners operating within resource-strapped healthcare services lacked opportunities to reflect upon their practice and identify the myriad factors combining to undermine patient engagement.

We don't spend time with finding out why people have disappeared or disengaged…they just become sicker and sicker, and then they are forced to seek services in an emergency situation, and so their whole interaction is much more stressful and fraught with all the angst that goes around emergency situations. [Non-Indigenous_Manager_F_Rem]

Discussion

In this multi-site study we explored barriers to and enablers of Aboriginal and Torres Strait Islander peoples' engagement with health services for chronic disease care over time. A number of factors were identified which enabled engagement. These included opportunities that arose after a life-threatening event, the motivation to engage with care in order to 'be there' for family, and the clear role healthcare practitioners played in this context. We identified a number of pivotal factors that appeared to drive some patients to disengage. These issues frequently occurred simultaneously, compounding and resulting in a tenuous context of engagement for many community participants. Engagement with care was also resisted by some patients in favour of living life on their own terms. This sometimes involved 'pushing back' against the system as a way to express dissatisfaction with, and exert some control over, systems of care.

Opportunities to Enhance Engagement

Despite a significant body of research examining Aboriginal and Torres Strait Islander peoples' access to health services, the evidence largely identifies barriers to care [15-21] rather than factors which enhance or enable engagement, particularly over the extended period necessary for chronic disease care. Although there have been some recent examples exploring increased access to and enhanced health service delivery for Aboriginal and Torres Strait Islander peoples [22, 23], perhaps one of the most important aspects of our work has been identifying motivating and enabling factors that provide insights into how to improve connections with patients in order to strengthen their capacity to manage chronic conditions and improve their health.

The Potential for Change

The first of the opportunities to enhance engagement relates to the period surrounding a health crisis, which can present significant challenges to a person's understanding of the world [24]. Our findings reveal that the experience of an acute and potentially life-threatening event can be perceived by some Aboriginal and Torres Strait Islander peoples as a motivation for change. Health crises brought some people to a 'fork in the road' and provided opportunities for them to reflect and consider the implications of such events, for themselves and their families.

Positive changes following a range of traumatic events are possible [25] and have been labelled 'thriving', 'blessings', 'positive adaptation' and 'perceived benefits' individually, and collectively as 'adversarial growth' [26]. A study by Affleck et al [27] showed that patients who perceive benefits following a heart attack are not only less likely to suffer a subsequent attack, but are also more likely to have better general health. Associations such as these suggest that clinicians should be aware of the potential for positive change amongst their clients following these events. As this can also be a time for making decisions, it affords opportunities to encourage and support people to live a healthier life [28], and practitioners and health services are key to facilitating these improvements. These positive changes could become the basis for further therapeutic engagement, including interventions targeting lifestyle and behaviour change sustained over time.

Some Considerations in Relation to the Role of 'Family'

Our finding of family as a motivator of engagement reinforces the centrality of family within Aboriginal and Torres Strait Islander peoples' lives [29] and suggests that improving engagement will in most cases involve working with patients and their families. A study of end-stage renal disease among Aboriginal peoples [30] found that the primary determinant of a patient's ability to manage their chronic illness involved family support. With encouragement from family, patients persevered; without this support, people "lost heart" (p. 75) and disengaged from care. Connection to family, peers and social networks has also been found to constitute a protective effect in relation to experiences of sub-optimal care [23]. Family and community members not only encourage negotiation and use of health services [15] but also provide solicited and unsolicited informal support for people with chronic illness [31].

It is important for healthcare providers to understand the cultural, historical, social and family contexts of their patients [31, 32] as these are all integral to the well-being of Indigenous peoples. The Whanau Ora philosophy developed for use in a number of Maori health services [33] articulates this. Whanau Ora is an inclusive approach, one anchored in a Maori worldview of health which assumes that by focussing on the family collective, changes can also be brought about in the wellbeing of individuals, and vice versa. Similarly, in Australia there is growing recognition that Aboriginal and Torres Strait Islander peoples do not view illness as the problem of the individual but as one impacting both the family and the community [31].

Despite community participants in our study noting the importance of family as a motivator, tensions between autonomy and relatedness within Aboriginal social life [34] may mean that some people, in some circumstances, do not want to fully disclose or discuss their health status with family members. Another study found that Aboriginal and Torres Strait Islander peoples placed great emphasis on not getting family directly involved in the management of their condition, preferring independence in this regard [31]. Although some were deeply grateful for family input, others expressed ambivalence toward 'messages' conveyed during acts of unsolicited support, especially when they took the form of nagging, 'growling' and surveillance. These forms of support draw on notions of responsibility to live healthily, and by extension to live for the family and are in keeping with our findings around 'being there for family' as a motivator for engagement. The role of 'family' in Aboriginal and Torres Strait Islander peoples' experience of chronic illness is therefore a complex one [30], and the development of family-based models of chronic disease care will need to take these tensions, complexity and heterogeneity of context into consideration. Improving health outcomes through increasing engagement will require unpacking and understanding the ways that

broader social and cultural contexts impact upon Aboriginal and Torres Strait Islander peoples with chronic illness [31].

Making the Most of Care Encounters

It is important for healthcare practitioners to understand that motivation for change cannot be imposed, but must be elicited. A number of models have been developed to better understand a patient's ability to engage in management of their chronic disease(s). Brief interventions were identified in the Australian National Chronic Disease Strategy as an evidence-based strategy to prevent, detect and manage chronic disease [35]. This approach focuses on "short, focused, non-judgemental, motivational patient-centred interactions that seek to change behaviour to achieve a healthy lifestyle" (p. 38). In essence, these interventions help clients recognise and respond to their current or potential problems. Motivational interviewing is one such approach which was mentioned in our study and has been described as a means to better understand the patient, as well as to explore and resolve ambivalence in relation to treatment [36]. Although there are many variations within motivational interviewing, the key is for the practitioner to be persuasive rather than coercive, supportive not argumentative, with the goal to increase the patient's intrinsic motivation so that change arises from within [37]. It is critical for practitioners to bear in mind that these methods are based on making patients aware of the potential for a change in behaviour, rather than focusing on a clinical outcome. Therefore even small changes are of interest if they represent the beginning of change for the patient [37] and, as indicated by practitioners in our study, should be acknowledged and supported.

Towards Patient-Provider Engagement

Given that healthcare systems are inherently relational, many of the critical problems facing them are relationship-based [38]. Approaches during clinical encounters which level power relations can help patients feel safer, facilitate sharing of healthcare needs and allow people to make choices as to their uptake of the information provided, including whether they can or will incorporate it into their day-to-day lives [32]. Our findings indicate that long-term, established relationships are most effective in sustaining the types of behaviour change required to improve health outcomes for people with chronic disease. This suggests that 'engagement' in relation to care for chronic disease is not the responsibility only of Aboriginal and Torres Strait Islander patients. Healthcare practitioners, too, need to engage in the process of building relationships with their clients as direct therapeutic benefits have been shown to result from the building of a trusting relationship between patients and providers [38].

Patient-provider engagement is the dynamic, two-way interface between a patient and a healthcare practitioner [39]. As our findings suggest, engagement is not homogenous, nor is it constant or automatic; it is all about relationships. Essentially patient-provider engagement describes the synergy between clinical competence, cultural respect and the shared understanding that occurs when healthcare providers acknowledge and nurture their patients' wellbeing. It is posited that patient-provider engagement is instrumental for improving healthcare and results in improved health outcomes; patient-provider engagement is fundamental to the process that defines the outcomes [39].

Stay or Go? Understanding Drivers of Tenuous Relationships and Disengagement

A number of studies have contributed to an improved understanding of the social, emotional and logistical challenges that underpin tenuous patient-provider relationships and/or drive Aboriginal and Torres Strait Islander peoples to disengage from healthcare [40-45]. Influencing factors include cultural differences, lack of culturally appropriate care, different constructs of health and illness, dislocation from family and country, cultural obligations, miscommunication, feelings of disempowerment, mistrust and racism. In addition, the concept of candidacy, which proposes that peoples' eligibility to access healthcare services is the product of negotiation between individuals and health services [46] may not apply in this context, given the tenuous relationships that we identified between some Aboriginal and Torres Strait Islander peoples and Western models of health service provision.

'Trust' is a relational notion, and concerns about the broader relationship between healthcare and society are reflected in the discourse surrounding the decline of popular trust in health systems [38]. Amongst colonised populations, historical trauma may influence the level of trust between Indigenous peoples and healthcare services [47]. The legacy of history may underpin some of the tenuous relationships identified in our study, as trusting relationships between patients and practitioners do not come easily and take time to establish and maintain. Trust is, at times, fragile and appears particularly vulnerable to logistics of care, such as health service delays. This can result in practitioners having to re-build relationships, or 're-earn their trust credentials' in order to re-engage patients in care.

Our findings indicate that experiences of racism and discrimination remain a contemporary reality for Aboriginal and Torres Strait Islander peoples engaging with the Australian healthcare system today. Similarly, racism has emerged as a key issue within other studies. Racism towards Indigenous patients in health services has been found to be multi-layered. It is institutional, interpersonal and internalised when Indigenous patients incorporated racist attitudes and beliefs into their lived experience, lowering their expectations and sense of self-worth [48]. Cox's [49] ethnographic research examined how race relations impacted upon health service providers' relationships with Australian Aboriginal peoples and the level of care they received. Cox found that 'health' was experienced as another institution and described a series of damning episodes where Aboriginal people were poorly treated. Other research has described Aboriginal peoples' experience of stereotyping and "underhanded racism" [42, p. 11], which also resonates with our findings. These may not be explicit but are often subtle systemic practices, almost invisible within individual patient-provider interactions which, although not necessarily ill-intentioned, remain discriminatory [50].

Voting with Our Feet

Discharge against medical advice is embedded within the National Aboriginal and Torres Strait Islander Health Performance Framework as an indirect indicator of the responsiveness of hospital services [51], and several studies have focussed specifically on this issue [21, 50-53]. Thomas et al. [21] revealed greater Indigenous than non-Indigenous dissatisfaction with care received within Australian emergency departments, with more Indigenous patients walking out of the facilities before being seen or before their treatment was completed than non-Indigenous patients. Indigenous patients were also 19 times more likely than non-Indigenous patients to be discharged against medical advice. Although Indigenous patients generally waited a similar, sometimes slightly

shorter, time to be seen compared to non-Indigenous patients, greater discontent and more frequent walk-outs may still be due to Indigenous patients' perceptions that they wait too long [21].

Despite evidence of greater dissatisfaction with care received in emergency departments among Indigenous, as compared to non-Indigenous patients, Thomas et al conceded the reasons why this was the case were unclear [21]. Yet the development of any strategy to help reduce self-discharge rates hinges on an appreciation of the factors that contribute to the decision to disengage [52]. In our study, waiting for care reinforced feelings of marginalisation and was raised by community participants as a driver for disengagement in relation to both primary and tertiary healthcare settings. Waiting made participants feel that they were being ignored, were invisible to healthcare providers and that the health system was indifferent to their needs. Especially when participants had many other demands competing for their time, waiting could become the issue that pushed people to the tipping point of disengagement.

Navigating Care on One's Own Terms

Our study showed that not all Aboriginal and Torres Strait Islander peoples completely disengage from healthcare, despite the challenges many encounter when they do engage. Some patients resist care or navigate the system on their own terms, despite the fact that this may endanger their health. Other research suggests that there remains a good deal more to be understood about what drives a patient's seemingly knowing forfeiture of their own treatment. Patterns of seeming avoidance or resistance such as repeated non-adherence with treatment may be a signal that patients are struggling to maintain engagement, or are becoming overwhelmed by their circumstances and need assistance [30]. In resisting the technical evidence base and the health practitioner's advice, patients are telling providers something important to heed and, critically, learn from [12]. Since these patients are not completely disengaging from the system, we argue that there is a very real opportunity for providers to re-engage with them, learn from these experiences and build the types of relationships which are needed in order to provide appropriate care.

Pushing Back: Understanding Avoidance of and Resistance to Engagement

The seeming resistance of Aboriginal and Torres Strait Islander people to engagement observed within our study may be the result of several influences. First to consider is that Aboriginal personhood is developed from an understanding of the social self. If one's autonomy can only be constructed out of relatedness, this also implies that one's physical wellness is measured by the extent to which it either impedes or enhances social interaction [54]. A practitioner in our study raised the important point that Aboriginal peoples with chronic disease may not see themselves as ill, especially if they can remain "productive" in ways consistent with their culture and participate in valued social activities, even if this interrupts their engagement with the healthcare service at times. Viewed from this perspective, 'resistance' may even be re-framed as a pursuit of wellness and wellbeing. However, this is not entirely compatible with a healthcare system that expects that people can and should put their 'selves' at the forefront of decisions relating to personal health and wellbeing [54]. In this sense, engagement can often require that Aboriginal and Torres Strait Islander peoples compromise their social obligations, creating conflict, and potentially avoidance and/or resistance.

A number of other researchers have explored why resistance or 'push back' may occur. Some consider that the "relentless emphasis on time, day, tablets and routine" [30, p. 159] may be

unfamiliar concepts for some Aboriginal and Torres Strait Islander patients, which may contribute to them feeling sick and tired of adhering to recommended treatments. Any underlying ambivalence, doubt, anxiety or outright disbelief that they are ill may also result in the patient behaving in a way which is inconsistent or unpredictable and, at times, viewed as self-destructive. Resisting or pushing back against care could also be a consequence of unplanned treatment initiation, communication difficulties between patient and provider, and a reluctance to relocate away from family and/or community. Feelings of loneliness could ultimately overpower a person's considerations of their own health, in turn inducing a "kind of fateful recklessness" [30, p. 155] in relation to engagement with care. Similar to the 'tipping points' we identified, in combination, these factors could take patients to the "breaking point" [55, p. 6].

Unintended consequences of health interventions could also include situations where the experience of feeling forced to follow a treatment regimen might result in a kind of rebellious non-compliance as patients reassert personal autonomy [31]. Prior research has identified the body as a site of resistance [34, 47] which can also be understood as "a plea for living on one's own terms" [47, p. 36]. However, some researchers have found that the reasons why patients behave in ways deemed self-destructive from a biomedical perspective, were neither clear, nor well-documented or understood [30]. We believe that our study may help to shed further light on this context, in particular the examples where a seemingly small or isolated issue, or an interpersonal conflict, appeared to provoke abrupt disengagement from care. Our findings indicate that a number of Aboriginal and Torres Strait Islander peoples had endured a succession of disappointments, frustrations and indignities within the healthcare system that, in some cases, got to the point at which one more compromise or negative experience became, for them, the final straw. Similarly, Cox found that each care encounter in which Aboriginal peoples were poorly treated "consolidates the fear, resistance, shame and avoidance historically associated with the health system" [49, p. 72-73]. This suggests that reactive disengagement results from the cumulative nature of patients' distressing experiences within the healthcare system.

Resistance behaviours may be an attempt to exert some control over a powerful system through avoidance and subversion, secondary to entrenched fear and mistrust which may underpin relations between Aboriginal peoples and state institutions [49]. The examples of 'pushing back' identified in our study should be considered against the backdrop of patients' previous adverse experiences, and the profound lack of power and autonomy many Aboriginal and Torres Strait Islander peoples continue to experience within the healthcare system [49, 56]. As both autonomy of action and belief in the right to control one's own body are inherent within Aboriginal social life [34], resistance to or 'push back' against engagement with care must be considered in light of this socio-cultural context.

An opportunity exists to re-frame providers' perspectives in regard to Aboriginal and Torres Strait Islander peoples resisting and/or 'pushing back' against the healthcare system. Healthcare practitioners are key agents of change who can pragmatically improve systems and reform ingrained discriminatory practices [48]. Rather than constructing patients as 'non-compliant' or unlikely to adhere to necessary chronic disease regimens, strategies to guide organisations in enhancing capacity for equity-oriented services recognise that broader contexts influence people's health decisions and trajectories [57]. In particular, an intersectional approach challenges how certain groups and individuals are problematised, critically questioning how problems are framed and highlighting the impact of the broader issues underpinning health problems. This has the potential to

change the manner in which both health services and healthcare providers respond [58]. A stance that problematises social structures and social suffering instead of individual people, allows providers to re-contextualise the 'tipping points,' 'resistance' and 'pushing back' identified in this study.

Strengths and Limitations

Broad strengths and limitations of this research have been previously described Monograph One of this series. An additional strength involves the innovative nature of this research, which has explored how to encourage Aboriginal and Torres Strait Islander peoples to remain engaged with care over time. With regard to the theme of navigating care on one's own terms, it is important to note that apart from one community participant's account, these stories were not obtained in the first person but instead were told by others. This could suggest that a tendency to resist, rebel or 'push back' against healthcare services and/or individual providers may be something perceived as being done by other people. However, we acknowledge that some community participants may also have been inhibited in their disclosure of personal accounts to interviewers who were either relatively unknown to them, or who were members of the health service they frequented.

Conclusion

Western health policy emphasises the responsibility of the individual to control their personal health fate, yet health status is not entirely a choice but the product of many historical, political, social and cultural determinants that are often not elaborated within the discourse of health and medicine [56]. The repercussions of colonisation, historical trauma and experiences of racism impact patient-provider encounters to this day, and these influences will likely go on to shape Aboriginal and Torres Strait Islander peoples' future encounters with health services. If not addressed, the inevitable result will be the ongoing production of a tenuous context of engagement for many.

The challenge for healthcare providers in this context is clear. If people continue to avoid, resist or refuse to access care, or only do so when they absolutely have to, improvements in health will not be achieved by simply providing more health services [49]. Solutions will not emerge as 'common sense,' nor will they be a matter of patients 'trying harder.' Efforts to understand Aboriginal and Torres Strait Islander peoples' health behaviours and patterns of engagement within the historical context are the necessary next steps in decolonising healthcare encounters [56, 59] and promoting among Indigenous people sustained engagement with care for chronic disease.

However, as our study shows, improvements as well as opportunities for further developments within the complex context of sustained engagement have been achieved. Approaches to lifestyle risk factor modification, which are flexible and fit with both episodic and ongoing patterns of engagement, appear to offer real opportunities to improve health outcomes. In keeping with the spirit of these approaches, many practitioner participants in our study remained open to the possibility of behaviour change, albeit incremental, amongst their clientele. Rather than the sole emphasis being on clinical endpoints, a focus on understanding patients' frame of reference is also critical. Building relationships which enhance and sustain the two-way interface of patient-provider engagement appears to be at the heart of the potential for change and making improvements in health outcomes for Aboriginal and Torres Strait Islander peoples with chronic disease.

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