



SHORT RESEARCH ARTICLE

Chronic disease self-management programs for Aboriginal and Torres Strait Islander people: Factors influencing participation in an urban setting

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Abstract

Issue addressed: Evidence suggests that participation in a Chronic Disease Self-Management (CDSM) program improves the health of clients. Many factors are known to influence participation in these programs for the broader Australian population. However, less is known about why Aboriginal and Torres Strait Islanders choose to participate. This study identifies key factors that support or enable Aboriginal and Torres Strait Islanders to participate in a CDSM program in an urban setting.

Methods: Twelve focus groups were undertaken with a total of 102 participants who were diagnosed with or at risk of chronic disease. These participants were recruited from the *Work It Out* program, a CDSM program comprising exercise and health education. The *Work It Out* program is specifically designed for Aboriginal and Torres Strait Islanders and delivered by an Aboriginal led and community-controlled organisation in South-East and Central Queensland. The study received ethical clearance through the Behavioural and Social Sciences Ethical Review Committee at The University of Queensland (Approval Number 2011001283).

Results: Findings indicate that key features of program design based on a culturally responsive approach influences participation. The main features are as follows: providing easy access to the program; permitting flexibility in attendance; a group environment; the approach of program staff that prioritises relationship building; personalised and integrated care; communicating result regularly; and ensuring community ownership of the program.

Conclusion: These findings are useful to consider when designing a health program for Aboriginal and Torres Strait Islanders. Programs which are culturally responsive and include the design features identified in this study are more likely to increase participation amongst Aboriginal and Torres Strait Islanders.

So What? Increasing participation of Aboriginal and Torres Strait Islanders in CDSM programs using the design features identified in the paper may contribute significantly in closing the health disparity gap.

Summary

This study identifies key factors that support or enable Aboriginal and Torres Strait Islanders to participate in a CDSM program in an urban setting. Increasing participation of Aboriginal and Torres Strait Islanders in CDSM programs using the design features identified in the paper may contribute significantly in closing in the health disparity gap.

KEYWORDS

chronic illness, health promotion, health services, indigenous, self-management, urban health

1 | INTRODUCTION

Providing services which are designed for and with Aboriginal and Torres Strait Islanders is key in closing the health disparity gap.¹⁻³ Chronic Disease is the main contributor to this gap yet there are very few Chronic Disease Self-Management (CDSM) programs designed for Aboriginal and Torres Strait Islander people.

CDSM programs have been shown to be effective in improving both physiological and socio-emotional well-being health outcomes for clients. CDSM programs include a range of activities that enable participants to cope with and manage the physical, psychosocial and emotional aspects of living with a chronic disease.⁴ These programs typically incorporate an educational component, often focusing on dietary changes and stress management techniques and some include physical exercise. While there remains little evidence as to a precise attendance frequency, research suggests that higher rates of attendance in CDSM programs correlate with greater improvements in health outcomes.^{5,6}

Many studies have investigated the myriad of factors that can act as barriers or enablers to program participation within the broader Australian population across many chronic disease conditions.⁷⁻⁹ This research suggests that the barriers and enablers of program attendance can be placed into four interconnected categories (i) intrapersonal, (ii) interpersonal, (iii) environmental and (iv) system level factors. Common examples of intrapersonal factors included physical pain, fear, knowledge of condition and services, health benefits, psycho-emotional factors, competing demands, perceived time availability and program acceptance. Key interpersonal factors included the relationships held with health professionals, perceived social support and family obligations. The most common environmental factors were occupational obligations, financial constraints, location, distance, transport options and weather, and the system level factors included health care delivery and program specifics (time, scheduling).

The few studies that have focused on Aboriginal and Torres Strait Islander populations engagement in CDSM programs have indicated that access to the program, allowing attendance to be flexible, group size and trust between staff and clients are key factors influencing participation.^{10,11} Programs delivered in an Aboriginal

and Torres Strait Islander community-controlled health service are also reported to yield greater participation.¹¹ Of critical importance is the extent to which the program is responsive to local processes and facilitates community ownership.¹

The World Health Organisation (WHO) promotes “social participation” to empower affected communities to increase control over their health, especially those who are vulnerable or excluded.¹² However, participation is more than just a principle for community engagement.¹³ Key to empowering Aboriginal and Torres Strait Islanders in health promotion is *meaningful* participation. This means ensuring Aboriginal and Torres Strait Islanders have control of the health promotion practice from start to finish and all design features are culturally responsive. Culturally responsive care has been defined as “an extension of patient-centred care that includes paying particular attention to social and cultural factors in managing medical encounters with patients from very different social and cultural backgrounds.”¹⁴ To ensure sustainable self-management of chronic disease for Aboriginal and Torres Strait Islanders, it is imperative to understand what inhibits or facilitates program participation over the long term.

2 | AIM

The aim of this qualitative study was to explore client perceptions of the factors that influence their participation in *Work It Out* – a CDSM and rehabilitation program designed for urban Aboriginal and Torres Strait Islanders in Queensland. Previous research has shown that *Work It Out* is effective in reducing indicators of chronic disease in urban Aboriginal and Torres Strait Islanders.¹⁵

3 | SERVICE CONTEXT

The *Work It Out* Program is delivered by The Institute for Urban Indigenous Health (IUIH). IUIH was formed by the four Aboriginal and Torres Strait Islander Community Controlled Health Services (ATSI CCHSs) in South-East Queensland in 2009. At the time of writing, IUIH comprised 20 Aboriginal Medical Services (AMS) or “clinics,” which are primary health care services that provide access to a range of

health professionals under one roof in the UIIH system of care, which is a “one-stop-shop” model of primary health service delivery (UIIH, 2017). The UIIH system of care aims to facilitate easy access and culturally responsive quality health services to Aboriginal and Torres Strait Islanders, led by Aboriginal and Torres Strait Islanders (UIIH, 2016).

The *Work It Out* program is a holistic CDSM program delivered by Aboriginal and/or Torres Strait Islanders and non-Indigenous health professionals working together in an Aboriginal Community Controlled framework. Staff include Aboriginal and/or Torres Strait Islanders and non-Indigenous allied health professionals along with Aboriginal Health Workers. The *Work It Out* program commenced in 2011 and is now operating at 15 locations in South East and central Queensland. Most locations have two sessions per week over a 12-week cycle. The program aims to improve clients’ ability to self-manage through collaborative relationships with health professionals. UIIH delivers the *Work It Out* program to South-East Queensland using a combination of Medicare-generated income and a contracted program fee in each location in order to provide the program at no cost to clients. The *Work It Out* program delivered at central Queensland locations is funded by Queensland Health.

In line with research regarding culturally responsive service delivery,^{16,17} the *Work It Out* program is delivered in a flexible manner that prioritises relationships, takes a social view of health that sees individual health as embedded in socio-cultural contexts, and values the cultural knowledge and connections of many participants. It encourages empowerment and supports self-management and ownership of one’s own health. Additionally, the program overcomes barriers to program access by providing transport, supporting staff through ongoing training regarding cultural responsiveness, utilising government funding and requiring no gap-payments by clients, and allowing clients to pause program participation and return to the program at times that suit them.

Each session comprises a group 45-minute “yarning”¹ (education) session facilitated by an inter-professional team including psychologists, dietitians, occupational therapists, researchers, nurses and diabetes educators; and 1 hour of tailored exercise supervised by an accredited exercise physiologist or physiotherapist. The session concludes with 15 minutes of “tukka” (a light snack). Entry into *Work It Out* is facilitated through a referral from a General Practitioner working within one of the 20 Aboriginal Medical Services or “clinics.” Results of the program are regularly fed back to clients individually by the exercise physiologists. Baseline data are collected at the beginning of each 12-week cycle and again during a “review” session at the end of the 12 weeks. This includes anthropometry measures, functional and aerobic capacity testing, and surveys assessing quality of life and psychological distress. Clients’ blood pressure and blood glucose level (if diabetic) are also taken at the beginning and end of each *Work It Out* Session.

4 | METHODS

Focus groups were undertaken at 12 locations where the program was implemented in urban South-East (9) and central Queensland

(3). These focus groups were undertaken by two non-Indigenous researchers² employed by UIIH over a 2-month period in August and September 2016. Qualitative research was informed by a strengths-based approach that draws on existing knowledge, skills and resources to improve delivery of health services.^{19,20} As opposed to problem-based questions, the focus group guide consisted of prompts to ask the participants about the main things that helped or supported them attending the program, with the overarching question “*What helps or supports you to attend Work It Out?*” These prompts were informed by the literature and included:

- Location of the program
- Frequency and length of the program
- Exercise component versus the yarning (education) component
- Participating in a group (size, dynamics, support)
- Workforce issues (staff knowledge of chronic disease, cultural awareness, turnover, support)
- Transport, money
- Family
- Other priorities

The focus group was run in an informal yarning style by researchers with extensive experience undertaking research involving Aboriginal and Torres Strait Islander people. Research Yarning has been established as a culturally appropriate methodology for research with Aboriginal and Torres Strait Islander people that takes place in order to gather information through participants’ stories that are related to the research topic.¹⁸ These discussions were recorded and transcribed verbatim. Focus groups ranged in size from 4 to 19 participants per location. The *Work It Out* program includes one session in each 12-week cycle that is dedicated to research and evaluation activities. This reflects research best practice by positioning Aboriginal and Torres Strait Islander people as equal partners in research.²¹ This can entail discussing the research program associated with *Work It Out*, reporting and discussing research findings, gathering service evaluation information for quality improvement, and the focus groups that contributed to this project. While the participatory nature of the program entails ongoing discussions with participants and modification of the program based on participants’ input into its design and delivery, these regular sessions ensure time is dedicated to listening to clients’ perspectives and incorporating their views in program planning along with research about the program. When focused on research activities, these sessions encourage discussion on the meaning of research, data and outcomes and seek input from participants. Focus groups were carried out as part of these regular program sessions, were all under 45 minutes in duration and took place directly after a *Work It Out* exercise session.

A total of 102 people (42% male, 58% female) aged between 18 and 80 years old who were diagnosed with or were at risk of chronic disease participated. Chronic diseases affecting participants

included hyperlipidaemia, asthma, hypertension, obesity/morbid obesity, osteoarthritis, Type 2 Diabetes, ischemic heart disease, chronic lung disease, hypothyroidism, obstructive sleep apnoea, anxiety and depression. Participants had been attending *Work It Out* between 1 week and 5 years. The great majority of participants identified as Aboriginal and/or Torres Strait Islander (90%), a small number of participants were non-Indigenous (10%) as they were regular clients of the Aboriginal and Torres Strait Islander Community Controlled Health Service.

Data analysis began with multiple readings and independent coding of a selection of transcripts by theme using Excel software (Microsoft, USA). The research team then reached consensus on a coding matrix and continued to code the data in more detail. Additional codes were developed inductively and agreed to in regular meetings of the research team. Researchers provided feedback regarding the themes to participants during a *Work It Out* education session. This provided an opportunity for member checking and enabled the research team to incorporate the participant's perspectives in the final description of findings.

The study received ethical clearance through the Behavioural and Social Sciences Ethical Review Committee at The University of Queensland and the Senior Management Team at IUIH. All regular clients (a total of 133) of *Work It Out* were invited to participate in the study 2 weeks prior to the focus group taking place and reminded at the *Work It Out* session 1 week prior to the focus group taking place. A total of 120 out of 133 regular clients volunteered to participate in the research. This invitation was given verbally by the regular exercise physiologist facilitating the program at each location. It was explained that participation in the focus group was voluntary, and they were welcome to not attend or to attend to listen only. All participants were given a written project information sheet and all participants provided written informed consent prior to their participation.

5 | RESULTS

Data analysis revealed a number of themes related to program design. The following summary provides the main themes identified and described by participants.

5.1 | Group environment: Making connections

The great majority of participants valued that the program was in a group setting with other people with similar health concerns and cultural backgrounds. The group environment provided support for individuals who were uncomfortable attending a gym, and encouragement for other challenges such as health or family issues. Whilst there were a few clients who struggled with the group setting at first due to mental health issues such as anxiety, the supportive environment encouraged them to stay. The connections provided by the group were seen by clients as critical in addressing their social isolation.

The social contact is terrific. You may be dealing with some problem and the person sitting next to you will say "oh try such and such" so you are always exchanging and getting advice from people who may be going through the same thing. Before this program we just stay home all day, but now we have all this social contact, it just enriches your life [Location 2].

I like meeting other Murri people around the area. You normally wouldn't socialise with them outside of here, a lot of people don't have access to transport. It's more than just the exercise you have other people to support [Location 3].

Yeah it is like we are a big family here. If anything is wrong you know we try and help each other. I think that is a bonus as well you know. I think finding family too between each other just for the people you didn't know before. Find our family, a proper family you know [Location 4].

5.2 | Approach of program staff: Valuing relationships and being respectful

In addition to the group support, participants noted the approach of staff who they viewed as being respectful of Aboriginal and Torres Strait Islander people and culture. Participants said they appreciated that staff acknowledge Traditional Owners³ prior to delivering their yarning (education) session. Participants also appreciated that staff take time to develop relationships with participants beyond their particular health concern. The health professionals who facilitate the education (yarning) component of *Work It Out* are also present during the exercise session and have a yarn with participants while they exercise. Participants enjoyed this additional contact with facilitators of the education component of the program and commented that this relationship made them feel more comfortable attending. Participants also commented that they liked the continuity of having the same exercise physiologist for each session. Much like the relationships they build with facilitators of the education session, having the same exercise physiologist enabled clients time to build a relationship and build trust. Comments included:

The communication is good, they let you know when things are happening, you feel respected [Location 6].

You guys help us with what we do and your experience... support you give us makes us feel good and we're not undershooting or overstepping the mark, we're just doing what we have to do and it works out [Location 10].

Yeah they're [exercise physiologists] not like those ones, you know those, what is it called, like the biggest losers that push you push you push you! They're not right there pushing you pushing you. [Location 11]

5.3 | Enabling access for participants

Of critical importance to many of the participants was that the program is cost free. Many said they could not afford to go to a gym or seek advice from health professionals without the program. Of equal importance was the transport service provided by the local Aboriginal community-controlled health clinic.

The transport is a very big thing. We get picked up, we get taken home and we don't have to pay for this which is another thing, because a lot of us are on pensions or some kind of support payment so to us this is a very very big thing [Location 2].

The program being connected to their Aboriginal-controlled health clinic and increased their level of comfort attending the program:

You could call it a type of safe place... because we can be who we are as our own people because we are together... we need space to express ourselves [Location 5].

I like the fact that the gym is so close, [to the clinic] that we can go over there together and um feel more comfortable with the group rather than having to walk into a gym on my own [Location 4]

I walked in the door [of the gym] and walked out the door cause I was having a panic attack and [the exercise physiologist] was like "What are you doing?" I said "I don't belong here, I don't fit in anywhere here look at everyone", and [the exercise physiologist] said "come with me come upstairs", and yeah we went from there [Location 8].

5.4 | Flexibility enables longer term participation

The *Work It Out* program was designed to have no defined entry or exit point. Self-management at *Work It Out* is defined as supporting ongoing engagement in the program as opposed to the expectation that this support is no longer required after one cycle (12 weeks). These design feature enabled participants to attend to personal commitments that arise during the program cycle, and return once they are free to do so. Reasons for not attending individual sessions mostly related to health factors such as illness, pain, being in hospital, poor mobility, injuries, anxiety and depression, and problems

associated with the commencement of new medication. The second most common response was attending sorry business⁴ or family commitments such as attending events at school, or caring for children, grandchildren and partners:

Culturally, my grandkids come before coming here, I am always going up at the school or something [Location 1].

Family is first priority, if I got a problem with my kids with school attendance and the principle ring up then I would not come [Location 8].

5.5 | Personalised and integrated care

There was a great appreciation amongst participants for the way in which the program was tailored for individuals. This included the exercise programs designed by accredited exercise physiologists based on the clients current health conditions and level of ability.

They tailor the exercises to your ability, they tell you the right way to do the exercises if you're doing it wrong, they will correct you [Location 7].

For each and every one of us with the different problems that we have we've had different programs set up for us that we can work through and it's monitored and just recently my weights have all gone up because I'm coping better with it and that sort of thing [Location 2].

The education yarning sessions are delivered by a range of allied health professionals, enabling access to health professionals that participants are unlikely to have contacted outside of the program. The presence of an Aboriginal health care worker at some locations also provided a critical link between participants and the Aboriginal community-controlled health clinic. These workers booked and followed-up appointments to ensure clients received any additional care required. For example, one client in this study had not visited a dentist for many years. He attended an appointment at the local clinic, but walked out during the consultation without explanation. The Aboriginal health care worker was able to follow-up with the client during a *Work It Out* session and discover that he was nervous, and encouraged him to try again. With this support, the client was able to attend another appointment successfully. When speaking about an Aboriginal health worker, one participant commented:

We would talk to her [the health worker] about most things and she would make appointments for us and follow up people who have missed a day and something... an encouraging phone call can help. You have

to be aware with our people that encouragement can be a big thing [Location 2].

5.6 | Empowering participants to self-manage

Many of the participants commented on the positive health outcomes (such as weight loss, lower sugar levels, or improved mental health) they experienced since joining the program. These results motivated them to continue with the program. Others commented on the sense of control they had to manage their own health into the future. Comments from participants included:

When I started I weighed 92 kilos and sugar levels are high and I lost 8 kilos, ten weeks ago they were going to put me on insulin but they're not now [Location 7].

Well I guess it makes you feel a bit better in yourself, and I guess you're taking an active role in your own health you know, you're participating [Location 10].

Results are regularly fed back to participants by the exercise physiologists individually, and group results and outcomes are discussed during the "Big Picture" research yarning sessions held once every 12 weeks. During these sessions participants are also encouraged to request information and suggest research ideas.

6 | DISCUSSION AND CONCLUSION

This study aimed to understand factors that influenced Aboriginal and Torres Strait Islanders to participate in a CDSM program in urban areas of South-East and Central Queensland. Results from the qualitative analysis revealed a number of program design features which helped facilitate discussion.

- 1 Meaningful participation through discussion and collaboration with participants and key community stakeholders
- 2 Group environment with other Aboriginal and/or Torres Strait Islanders
- 3 Employing Aboriginal and Torres Strait Islander people to deliver the program and non-Indigenous staff who recognise the centrality of relationships in providing culturally responsive care
- 4 Providing free access and transport to program
- 5 Integrating the program with Aboriginal Medical Services (AMS)
- 6 Providing flexibility in program attendance (no specific entry and exit point, absences without penalty)

Work It Out was developed and is driven by Aboriginal and/or Torres Strait Islander health professionals, community members and community-controlled health services. Participants and key community stakeholders are given ongoing opportunities to provide informal and formal feedback to program staff so their perspectives are

incorporated into all aspects of the program. Communicating program results on a regular basis and including participants in the design of any research activities.

For those attending *Work it Out*, the opportunity for social interaction was a key factor identified by participants in helping foster "re-connectedness" in an urban context.²² This is consistent with previous mainstream literature which identified a modest positive relationship between social support and chronic illness self-management.²³ Also consistent with previous literature regarding health service delivery for Indigenous Australians,²⁴ good relationships between staff and participants were also identified as critical to *Work It Out* clients' decision to participate in the program. The importance of relationship-based practice to providing culturally responsive health services is well established.²⁴⁻²⁶ Nelson's "Making Connections Framework"²⁶ explains that the health professional must move beyond building a relationship with the individual, to establishing relationships with the clients' family, community and other health services available to them. Participants in this study valued that facilitators of the program had a yarn with them rather than, for example, prioritising the completion of a specific exercise program for the day.

Of critical importance for many of the participants in this study was that the program was cost free, and transport was provided by a local Aboriginal driver employed by the participants local Aboriginal Medical Centre. Without this kind of access to the program, the majority would not be able to attend. Another positive finding in this study was that the program helps to connect participants to health professionals at their local Aboriginal Medical Centre. Moreover, the presence of an Aboriginal health worker at some programs can provide further support in facilitating appointments with the clinic. The Aboriginal health worker attending *Work It Out* plays a vital role in building relationships with participants, offering support where needed and linking participants with clinic services where necessary for more effective communication, integration and outcomes. They are present to collect blood pressure and sugar readings, and support the exercise physiologist during program delivery.

The participants also valued the Aboriginal and/or Torres Strait Islander staff in service delivery. In total, 51% of UIIH's workforce identifies as Aboriginal and/or Torres Strait Islander. In addition to the Aboriginal and/or Torres Strait Islander transport drivers and health workers, 23% of health professionals involved in facilitating the yarning education sessions identify as Aboriginal and/or Torres Strait Islander. These staff ensure that all information in yarning (education) sessions is accessible, culturally relevant and utilises local knowledge. For example, the education component uses yarning rather than traditional didactic teaching. All participants sit in a yarning circle with the health professional and share stories about the topic scheduled for that day. Communication is two-way, with the health professionals also learning from the participants. Local knowledge is incorporated by seeking input from local Aboriginal and Torres Strait Islander UIIH staff and participants themselves. For example, local traditional foods are incorporated into the dieticians' education session where possible. All employees involved in the delivery of the program complete

cultural training prior to facilitating a session. In addition, IUIH has developed a Cultural Integrity Investment Framework to embed Indigenous "Ways" into all that it does. "The Ways Statement" are the expressions of cultural and philosophical understanding which become the foundations on which organisational and operational processes are embraced. All employees are required to continually reflect on their practice and "The Ways" at regular staff meetings.

Another key feature identified by *Work It Out* participants in this study was the programs flexibility in regard to attendance. Participants felt comfortable taking time away from the program when they needed to, and this enabled them to participate longer term. This provides further support to the suggestion that flexibility is a key feature of successful approaches to health care provision for Aboriginal and Torres Strait Islanders.²⁴ Further, programs with flexible participatory approaches and long-term interventions often yield the greatest benefits for participants.²⁷

The results of this study support previous research that attributed the success of *Work it Out* to its flexibility, comfortable setting and the approach of staff ("skilled, accepting, friendly, culturally aware").²⁸ Importantly, *Work It Out* puts relationships at the centre of program design and staff consider program participants as the "owners" of the program.

While this study provides some insight into the factors that influence participation for Aboriginal and Torres Strait Islanders in the *Work It Out* program, further research is needed. Future research should look to interview *Work It Out* clients who have left the program to provide a better indication of barriers to participation.

CONFLICT OF INTEREST

The authors declare they have no conflict of interest.

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ENDNOTES

¹ Yarning (talking informally) is a dialogical process that is reciprocal and mutual.¹⁸

² These researchers are also authors of this paper. Both researchers have extensive experience undertaking research with Aboriginal and Torres Strait Islander people and deliver the "Big Picture" research sessions once every 12 weeks during the *Work It Out* Program.

³ The term "Traditional Owners" arose from its use in the *Aboriginal Land Rights (N.T.) Act of 1976* and has become widely adopted across

Australia to refer to people of Aboriginal ancestry who hold customary rights in land and waters.

⁴ Sorry Business is a term used by Aboriginal and Torres Strait Islander people to refer to death and mourning.

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