

## REVIEW ARTICLE

# Navigating the cancer journey: A review of patient navigator programs for Indigenous cancer patients

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## Abstract

Patient navigator programs have evolved to facilitate access to care and improve outcomes for Indigenous cancer patients. We reviewed the scientific literature on patient navigator programs in Indigenous people with cancer. We conducted a review of the published literature up to 13 April 2011. PubMed, MEDLINE and CINAHL databases were searched for original articles on Indigenous patient navigation programs. The review produced eight relevant articles covering two specific programs, the Native Sisters Program and the Walking Forward Program. Program descriptions, patient navigator's roles, cultural aspects and the impact of the programs were described. Patient navigators' roles in the programs varied, as did their qualifications, but importantly, all were Indigenous. Both programs aimed to increase participation in screening, remove barriers to treatment and decrease mortality. The Native Sisters Program documented an increase in adherence to breast screening among navigated American Indian participants, although there were substantial differences in the baseline screening adherence between navigated and non-navigated participants. The Walking Forward Program yielded on average 3 fewer days of treatment delays for navigated American Indians than for non-navigated American Indians. However, adjustments for socioeconomic characteristics and disease characteristics were not described. Although preliminary outcomes are seemingly positive, further rigorous evaluation of quantitative impacts are needed.

**Key words:** cancer care, Indigenous, neoplasm, patient navigator.

## INTRODUCTION

Despite the fact that global cancer incidence rates among Indigenous people are lower than or similar to that of their non-Indigenous counterparts,<sup>1-3</sup> cancer mortality is generally higher for Indigenous people around the world. For example, in Australia mortality rates are up to 45% higher for Indigenous people than for other Australians.<sup>1</sup> Additionally, due to the paucity

of adequate and reliable data on Indigenous status the true burden of cancer is likely to be underrepresented for Indigenous groups.<sup>4</sup>

The reasons underlying these disparities in cancer outcomes are multifactorial and all are not fully understood. These reasons are likely to include delays in diagnosis,<sup>5,6</sup> reduced uptake of or access to screening<sup>1</sup> and treatment,<sup>6</sup> higher rates of co-morbidities,<sup>6</sup> language barriers<sup>5</sup> as well as differences in socioeconomic status, poorer health behavior<sup>7</sup> and cultural factors.<sup>1,5,6,8</sup> Navigating one's way through the complex health-care system for cancer care can be arduous and fraught with uncertainty and fear for any individual with cancer.<sup>9</sup> However, these difficulties can be exacerbated for Indigenous people, who might not always utilize or understand Western health-care systems. Methods to reduce

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Conflict of interest disclosures: none.

Accepted for publication 20 January 2012.

these disparities are being explored across the world and one such method is the use of patient navigation (PN).

In the past decade there has been considerable interest in the role of PN in addressing systematic problems in access to health care and continuity of care for cancer patients. The very first patient navigation program (PNP) was established in Harlem, New York, in 1990 to address perceived barriers stemming from mistrust, fatalistic views and system complexity experienced by medically underserved, generally African American women, with breast cancer.<sup>10</sup> This program trained lay individuals to provide one-on-one support during treatment and beyond to women with breast cancer who had a poor prognosis.<sup>10,11</sup> Since then, PNP have become more widely used, particularly in the USA and Canada, and have expanded to not only inform patients about cancer and the availability of services, but also to address cultural, educational and language barriers to screening and treatment through community outreach by utilizing community health care workers.<sup>11</sup> The role of the PN in these programs has also evolved. In principle PN help individuals to navigate their way through their cancer journey and the health-care system by assisting them to overcome barriers to receiving timely cancer-related care.<sup>9</sup>

A review of 16 PNP in non-Indigenous groups by Wells *et al*<sup>9</sup> reported that, despite some improvements in the screening and re-screening rates of participants attending PNP, there remain many questions about the efficacy of PNP.<sup>9</sup> The authors concluded that more rigorous evaluations of such programs will be necessary to ensure the efficacy of future programs.<sup>9</sup> Given the additional complexities that may arise for Indigenous cancer patients, a review of PNP specifically for Indigenous populations is an important contribution.

Therefore, the aims of this review were to: (i) document the published literature on PNP for Indigenous people with cancer; (ii) describe these programs in relation to their service characteristics (services offered, navigator staff and their role and the cultural aspect of the programs); and (iii) document, where available, outcome measures and program impact.

## METHODS

A search of online peer-reviewed journal articles indexed in PubMed, MEDLINE and CINAHL before 13 April 2011 was undertaken. Citations that included the following terms in either the title, abstract, article or MeSH heading were selected: neoplasm\*, Navigat\*, Native Sisters, cancer care coordinator, Aboriginal, Torres

Strait Islander, Maori, American Samoa, Indian, North American, Inuit, Metis, Eskimo, Alaska/an Native, Aleut, Oceanic Ancestry Group, American Native Continental Ancestry Group. A short list of these articles was created by reviewing the title and abstract against our inclusion criteria, which specified that the publication had to: (i) be an original article; (ii) focus on a PNP related to cancer care; and (iii) target an Indigenous group. The reference lists of shortlisted articles were reviewed for additional articles that met our inclusion criteria.

## RESULTS

The initial search produced 58 records for consideration, of which seven met our inclusion criteria. A further review of the reference lists of these articles identified one additional article.

All eight articles reviewed (Table 1), described PNP that were conducted in the USA. These eight articles reported on two specific PNP, namely the Native Sisters Program and the Walking Forward Program. The type of publication of the reviewed articles varied from program descriptions ( $n = 4$ ) to original research articles ( $n = 4$ ). Where possible, we compare programs details below.

### Description of the PNP and their intended goals

The Native Sisters Program<sup>12,13</sup> focused on increasing the recruitment of Native American women into mammography screening to maximize the potential for early diagnosis of breast cancer. It did this by employing Native American women as PN (called Native Sisters). The Native Sisters took a leadership role in identifying and recruiting Native American women for breast cancer screening. They also supported them by attending screening appointments to ease any anxiety or trauma, or both, and assisting women in preparing questions to ask health-care professionals. Assistance and support, if required, is also provided to the patient's family. The Native Sisters program also assisted women and their families to navigate their way through the health-care system if a cancer diagnosis was made. Dignan *et al.* (2005) reported that all participants underwent at least one session with the PN either face-to-face or by telephone. These sessions ranged from 20 to 90 min in length but it is unclear how many interactions the PN had with each participant.

Table 1 Studies reviewed

Citation	Cancer site	Type of article	Aims and description	Participants	Navigators and their roles	Findings	Limitations
Native Sisters Program Burhanstipanov <i>et al.</i> , 1998 <sup>12</sup>	Breast	Program description	To increase recruitment for breast screening (initial and follow up) to maximize the potential for early diagnosis. To determine self-reported factors, via a patient inventory, to assist participation in screening of a navigator intervention (delivered face-to-face or by telephone) in increasing adherence to guidelines for mammography screening. Random allocation of a navigator (face-to-face, telephone, or no intervention). A printed brochure, tailored to individual women's risk factors for breast cancer was given to the intervention groups.	AI women (Los Angeles and Denver)	Trained AI women (Native Sisters) recruit patients for breast screening and follow up. They have 10 main tasks, e.g., providing emotional support for cancer screening and follow-up procedures and to providing education on breast cancer risks	Achieved 90% rescreening rate at recommended intervals Use of Native Sisters was reported to be the most effective strategy in getting patients to undertake screening	No report of screening rates of the participants at baseline No reporting of number of participants recruited into this program or their age at recruitment
Dignan <i>et al.</i> , 2005 <sup>13</sup>	Breast	Original research	To test the relative effectiveness of a navigator intervention (delivered face-to-face or by telephone) in increasing adherence to guidelines for mammography screening. Random allocation of a navigator (face-to-face, telephone, or no intervention). A printed brochure, tailored to individual women's risk factors for breast cancer was given to the intervention groups.	157 urban AI women 40-years old and over (Denver, Colorado)	Trained AI women (Native Sisters) provided information on breast cancer, the importance to a mammography and adherence to guidelines, strategies to overcome barriers to obtaining mammograms and assistance with referrals and follow up care	Navigators can be effective ( $P = 0.013$ ) in increasing adherence to screening guidelines: mammograms in the past year increased from 29 to 41.3% in the telephone group ( $P = 0.029$ ), and from 34.4 to 45.2% in the face-to-face group ( $P = 0.197$ ). The control group stayed about the same from 50 to 51.9%. The telephone method of navigating is feasible and less expensive than face to face	Only 17% ( $n = 137$ ) of potential participants ( $n = 929$ ) were recruited to the study; 29% loss of participants at follow up. Randomization did not achieve its aim as the control group was too dissimilar to the other two intervention groups
Walking Forward Project Petreit <i>et al.</i> , 2005 <sup>14</sup>	Breast Prostate	Program description	To increase participation of AI in clinical trials; to examine potential barriers to accessing the best cancer treatments (a general population survey [ $N = 1000$ ]); to develop culturally relevant education modules on breast and prostate cancers that may influence earlier diagnosis and increase the no. of patients eligible for participation in radiation therapy clinical trials	AI (western South Dakota) 1 urban and 3 reservations	Community research representatives (trained lay health advisers) provide: culturally appropriate cancer prevention education and assist with access to health-care services to allow for early diagnosis and treatment and navigating health-care and insurance systems. They also provide: emotional, social and logistical support and assist in the recruitment of patients in clinical trials and reduce dropout rates	No published results available	No preliminary results presented
Molloy <i>et al.</i> , 2007 <sup>16</sup>	All cancers	Program description	To describe programs that have fostered trust and increased the ability of patients to actively participate in cancer treatment	AI (western South Dakota)	Patient navigators (nurses) guide patients through the health-care system and address health-care issues; develop relationships with patients and their family; collaborate with health providers; track interventions and outcomes; advocate pain control, address treatment needs, the management of side-effects and end-of-life issues and access durable medical equipment for patients	Cultural competence in patient navigation programs delivered by the Walking Forward Program enhances patient care and plays an integral role in the patients' adherence to their cancer treatment regimes	Results regarding the impact of patient navigation in reducing treatment interruption require reference to the study or program from which they come
Peterit <i>et al.</i> , 2008 <sup>3</sup>	All cancers	Original research	To describe two navigator strategies: in cancer centers and on reservations Retrospective analysis to determine if navigated patients ( $n = 42$ ) undergoing curative radiotherapy had fewer treatment interruptions than non-navigated patients ( $n = 74$ )	213 AI (western South Dakota)	Hospital-based navigators (nurses) help: create a friendly cancer centre environment; assist with insurance issues; reduce logistical barriers to treatment and provide patient support and management services Community-based navigators (community research representatives) live in the community and assist with cancer education and resources; networking and liaising between health; professionals/services and program staff and data collection	213 AI with cancer have undergone patient navigation The median number of patient navigation interactions for AI patients undergoing potentially curative cancer treatment for cervical and head and neck cancer was 15 (range 1–95) Navigated AI had on average of 3 fewer days of interruptions than non-navigated patients ( $P = 0.002$ , $N = 116$ ).	The potential total pool of participants is unknown, as is how many declined to participate. The specific details of recruitment processes are not reported. The results presented give no description of the statistical methods used and it is unclear what potential confounders have/have not been adjusted for to interpret these results correctly

Table 1 Continued

Citation	Cancer site	Type of article	Aims and description	Participants	Navigators and their roles	Findings	Limitations
Peterit <i>et al.</i> , 2008 <sup>15</sup>	All cancers	Program description/lessons learnt	To describe the process of establishing a trusting partnership with AI communities (patient navigators are included in this process); to secure approval of study protocols for the Walking Forward program	AI (western South Dakota)	Patient navigators (AI nurses) assist patients with: assessing their support systems and cultural beliefs; addressing their specific needs to complete their treatment; and logistical issues for their accommodation, meals, insurance and transportation	10 lessons learned were identified in developing trusting partnerships with AI communities Increased community-based referrals and 26 AI have consented to participate in the project	Increasing AI patient recruitment is reported since this partnership was established; however no reports of the number of referrals prior to this is given
Kanekar and Peterit, 2009 <sup>17</sup>	All cancers	Original research/program description	To enrol AI in cancer treatment clinical trials by: identifying barriers to cancer care through community and prospective patient surveys (including medical mistrust and satisfaction with health-care scales); implementing a PN program; enhancing recruitment and conducting translational research	AI (western South Dakota) Survey: AI community (N = 984); patients newly diagnosed (N = 165; 52 were AI).	Hospital-based patient navigators assist with overcoming identified barriers (e.g., financial, social and emotional support) to cancer-related care and follow up. Community-based research representatives assist with education (screening, clinical trials)	Barriers identified in survey: Community: lack of transport (47%); not satisfied with interactions with medical providers, difficulty in accessing cancer screening, cost of food, transport and lodging; Patients: AI reported higher levels of mistrust ( $P = 0.0001$ ) and lower satisfaction ( $P = 0.0001$ ) with health-care than Whites. AI had higher rates of advanced-stage disease for screen-detectable cancers; Retrospective analysis comparing navigated-patients with non-navigated patients. Navigated patients ( $n = 42$ ) receiving chemotherapy and radiotherapy for cervical and head and neck cancer had a treatment delay of 1.5 days vs 4.5 days for non-navigated patients ( $n = 74$ ) ( $P = 0.0002$ ; C.I 95%) Accrual rate in clinical trials increased from 1% (USA) to 25% for AI after the program was implemented.	Survey: percentages not given for all the stated barriers and no raw data given. No details of medical mistrust and satisfaction with health-care scales were given. Results of retrospective analysis already reported by Molloy <i>et al.</i> , 2007 and Peterit <i>et al.</i> , 2008.
Guadagnolo <i>et al.</i> , 2010 <sup>18</sup>	All	Original research	Report on the accrual of cancer patients to clinical trials and document primary reasons for non-participation in a rural, community hospital setting. AI patients were referred to a patient navigator to assist in navigating the system.	Patients presenting to Rapid City Regional Hospital Cancer Care Institute (N = 891; 94 were AI).	All AI patients who presented were offered a patient navigation service. Patients were assisted by trained, culturally competent staff to serve as navigators starting from presentation for evaluation through to treatment.	Six, of 94 AI enrolled in a clinical trial. 88 AI did not enrol in a trial due to advanced stage/poor performance status/comorbidities ( $n = 24$ , 27%); no protocol for tumor site ( $n = 21$ , 24%); other reasons for ineligibility after evaluation ( $n = 20$ , 23%); physician judgment/trial treatment not appropriate ( $n = 18$ , 20%); patient refused/preferred standard treatment/preferred no treatment ( $n = 4$ , 4%); and 1 (1%) denied trial treatment coverage. Three (3%) AI patients enrolled in a cancer control/non-treatment trial. The total no of AI patients enrolled on a cancer treatment/control protocol was 9 (10%; 95% CI, 5–17%).	Eligibility rates could not be calculated and the validation of all new cancer cases was not performed for this cohort using registries and ICD-9 codes.

AI, American Indian. ICD-9, International Classification of Disease, 9th edn.

The main purpose of the Walking Forward Program was to reduce cancer mortality rates for Native Americans in three Lakota tribes in western South Dakota (Oglala, Rosebud, and Cheyenne River Sioux tribes) as well as one urban city (Rapid City).<sup>3,14–18</sup> The program employed community-based PN to deliver culturally appropriate community education about the value of screening and early detection and research. These PN played an important cultural role in developing a rapport with the community and reducing resistance to community engagement in clinical care and research activities. Additionally, hospital-based PN with ties to the community were used to provide assistance to participants who developed cancer to overcome financial, social and emotional barriers to receiving cancer-related care, including treatment and follow-up and palliative care.<sup>16,17</sup> PN also encouraged patients to participate in clinical trials.<sup>18</sup> Participants undergoing cancer treatment received around \$1000 to assist with food, transportation and lodging.<sup>15</sup> Participants undergoing treatment had on average 15 (range 1 to 95) interactions with the PN and participants in the post-treatment follow-up phase of care received on average four (range 1–26) PN interactions.<sup>15</sup> A PN interaction was defined as a person-to-person contact or telephone call.<sup>15</sup> PN also regularly review patient hospital accounts to identify potential patients who may be eligible for other benefits such as Medicaid and Medicare.<sup>15</sup>

### The patient navigators' role and training

In the articles reviewed the term “patient navigator” is used interchangeably with “Native Sisters” and “community-based research representatives”. PN in these programs provided education about cancer to the participants and their families on the importance of screening for early detection. They used written materials and had discussions about diagnostic testing or treatment options and side-effects, and on possible genetic testing.<sup>3,12–18</sup> Specific barriers to care were identified for each patient and addressed by the PN through a combination of strategies including organizing the participants' transport, scheduling multiple appointments on one day, facilitating child-care, looking into insurance issues or financial support and facilitating communication both in terms of translation and explaining health terminology.<sup>3,12–18</sup> Furthermore, the PN built personal relationships with the participants, thus providing emotional support; they talked to the participants about all aspects of their cancer care and informed them about different support group and counselling options.<sup>3,12,14–18</sup>

There was a clear distinction between the roles of the community-based PN and the hospital-based PN. Community-based PN largely focused on awareness and prevention of cancer, networking and the maintenance of relationships with local health agencies, whereas hospital-based PN primarily assisted Indigenous people with cancer through their cancer-related treatment and social and emotional issues.<sup>15</sup>

The background of PN ranged from lay individuals who were leaders in their community<sup>13–15,17</sup> to registered nurses.<sup>3,12,16</sup> PN in both programs received training about their role and were reported to have been equipped with the tools to provide a seamless path from screening to treatment and follow up while being culturally competent (this is discussed below).<sup>3,12–17</sup> However, the scope of this training is unclear in the published literature.

### Cultural aspects of the PNP

There are several areas in which the PNP incorporated cultural aspects into their programs. Both programs had cultural competency components that included acknowledging Indigenous peoples' history, promoting awareness of diversity among human beings, ensuring the ability to care for individuals and advocating a non-judgmental openness towards all.<sup>16</sup>

Both programs reported that building trust between PNP staff and the community was imperative across all project stages including: (i) during concept development, with an input from the tribal council and an upfront commitment from the research team to provide needed services; (ii) cultural competency training for the PNP staff which acknowledged Indigenous peoples' history and ensured that PNP staff were culturally sensitive to the needs of the community and individuals; (iii) during program delivery, where time was taken to educate the community about the program and answer their questions; and (iv) during program evaluation, where the results were shared with the community. These initiatives reportedly resulted in patients having established a level of trust with staff that allowed them to openly discuss their concerns. Furthermore, having a PN with an Indigenous background,<sup>3,12–17</sup> a culturally relevant educational materials (e.g., culturally tailored and appropriate brochures),<sup>13,15</sup> and the use of the local language or an interpreters<sup>15,18</sup> were also deemed to be important features of the PNP reviewed.

### Outcomes of the PNP

The articles published by the Native Sisters Program reported on the effectiveness of delivering the program



using different methods of navigation (i.e., face-to-face *vs* telephone *vs* usual care) on breast rescreening rates (see Table 1). Burhansstipanov *et al.* reported a 90% breast re-screening rate for American Indian women who utilized the PNP compared with the Centre for Disease Control database, which reports only a 50% rescreening rate among all women who use state-supported screening services at the recommended intervals.<sup>12</sup> However, the number of study participants in this analysis and their socioeconomic details were not reported, nor were the baseline screening rate of participants.

Dignan *et al.* reported randomly allocating participants in the Native Sisters Program to one of three study arms (face-to-face PN, telephone PN or no PN intervention) and evaluating American Indian women's adherence to breast screening over a 12-month period. The results from this study indicated that there was an increase in adherence to breast screening guidelines over the 12-month period in participants in both the face-to-face and telephone arms. The proportion of Indigenous women obtaining breast screening with self-reported mammograms in the intervention year increased from 29–41.3% in the telephone group ( $P = 0.029$ ) and from 34.4–45.2% in the face-to-face group ( $P = 0.197$ ). While by comparison, there was no significant change (51.9–50%) reported for the control group it is important to note that the baseline screening rate in this group was already high. The substantial difference between the baseline screening rates in the three study arms is of concern and indicates that the randomization to the three arms was unsuccessful in stratifying for known prognostic variables. Furthermore, only 17% ( $n = 157$ ) from a total of 929 potential participants were recruited in this study and 29% of these 157 were lost to follow up. It is unclear if the figures stated above include the participants who were lost to follow up or not.

The outcomes from various aspects of the Walking Forward Program are reported in six publications and are described in Table 1. Over 200 American Indian cancer patients were navigated.<sup>15</sup> While there were no reported rates of referrals for American Indian patients from community-based health services to cancer centres prior to the introduction of the PNP, the cooperative nature of the partnerships between the Walking Forward research team and American Indian communities was reported as having a positive impact on the number of patients receiving such referrals.<sup>3</sup> A retrospective analysis found that American Indian cancer patients receiving radiotherapy who were navigated

after a diagnosis of cancer ( $n = 42$ ) had on average 3 fewer days of treatment delays than non-navigated American Indian cancer patients receiving radiotherapy ( $n = 74$ ) ( $P = 0.002$ ,  $n = 116$ ).<sup>15–17</sup> However, in this analysis it is not clear what socioeconomic or disease characteristics have been controlled for (if any); thus, it is not possible to examine if these findings are truly due to the PN or are possibly just group-level differences.

The potential barriers to accessing the best cancer services and treatments were investigated through surveys of the community ( $N = 984$ ) and newly diagnosed cancer patients ( $N = 165$ , of whom 52 were American Indian patients).<sup>17</sup> While the proportions resulting from these surveys were not specifically reported, it was stated that the key barriers to American Indians accessing cancer care included the cost of transport, food and lodging; difficulties in accessing quality care and cancer screening; a lack of satisfaction with interactions with medical providers and a lack of confidence in their abilities. The most common barrier was reported to be lack of transportation, with approximately one in two patients identifying this as a barrier. The patient surveys also included scales to assess the patients' mistrust of medicine and their satisfaction with health-care.<sup>17</sup> While the exact details of these scales, like the number of items on them, are not reported, the authors state that American Indians had higher levels of mistrust ( $P = 0.0001$ ) and lower satisfaction ( $P = 0.0001$ ) with health care than Whites. A study of newly diagnosed cancer patients indicated that American Indian patients presented with higher rates of advanced-stage disease for detectable cancers.<sup>17</sup>

A prospective analysis of enrolment incidence in clinical trial recruitment using a PN (as part of the Walking Forward Program) for American Indian patients was assessed.<sup>18</sup> Of the 891 new cancer patients who presented, 94 were American Indian. Of the 94, six American Indian patients were enrolled on a clinical treatment trial and three were enrolled under a non-treatment cancer control trial, bringing the total to 10% and all underwent PN. This study reported higher accrual rates of American Indian patients to clinical trials than reported in other studies. However, the direct relationship of the documented increase in accrual in American Indian patients in relation to the use of a PN was not measured and thus it may be due to chance.

To date screening adherence outcomes for the Walking Forward Program have not been published nor has the survival outcomes associated with their PNP.

## DISCUSSION

This review highlights the dearth of published research articles on PNP for Indigenous populations. The eight articles identified to date provided information on two programs. While they vary to some degree, the programs share the common theme of attempting to provide a culturally competent service to reduce cancer mortality in Indigenous people through increasing cancer screening and assisting with follow-up care coordination. The existing articles do, however, provide some important insights into the roles of the PN and the delicate interface they play between the community and the health-care system.

The Walking Forward Program has not yet published survival outcomes despite its aim to bring about a reduction in the mortality rate. The current articles associated with these programs focus on program descriptions and intermediate outcomes including patients' adherence to regular screening, and describing their PNP. There is an indication that the use of PN improves breast screening adherence for Indigenous patients with poor pre-screening rates at baseline, together with increased enrolment in clinical trials and that the use of a PN may result in less treatment delays for American Indians with cancer. However, the true impact of these programs is questionable due to unsuccessful stratification in the screening trial and insufficient information given about participants' and non-participants' characteristics and insufficient information about any adjustments in the statistical models used in the observational studies.

The efficacy of PNP in non-Indigenous and Indigenous groups remains unclear. This review, while focusing on PNP for Indigenous people with cancer, confirmed reports by Wells *et al*<sup>9</sup> that there are no consistent approaches to program design or to the definition, role and training of the PN. Further, it remains unclear which navigator characteristics, that is, Indigenous background, lay person, practical support or emotional support, are most pertinent to Indigenous people to improve their cancer outcomes. This lack of consistency and the absence of comprehensive program evaluation have resulted in unsubstantiated and generalized conclusions being reported.

Models of care with similar characteristics to PNP have worked in other areas of Indigenous health.<sup>19</sup> The contributions that PNP can have in reducing the disparities in cancer outcomes for Indigenous people cannot be understated but they cannot be quantified at present. It is advisable, given such inconsistencies in the current

literature, that future programs should address these issues to ensure the scientific rigor of the program and its outcomes.

## ACKNOWLEDGMENT

Lisa Whop was a Master of Applied Epidemiology (MAE) scholar at the National Centre for Epidemiology and Population Health at the Australian National University and the Queensland Institute of Medical Research at the time this study was undertaken. The MAE program is funded by the Australian Government Department of Health and Ageing. PC Valery was supported by an Australian Research Council Future Fellowship (#FT100100511). This study was supported by the National Health and Medical Research Council (Project Grant #552414).

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