

Supporting Information

Supplementary methods and results

This appendix was part of the submitted manuscript and has been peer reviewed. It is posted as supplied by the authors.

Appendix to: Dissanayake HUW, Gurruwiwi G, Dhurrkay J, et al. Improving cardiometabolic risk factors in Aboriginal and Torres Strait Islander people in northeast Arnhem Land: single arm trial of a co-designed dietary and lifestyle program. *Med J Aust* 2025; doi: 10.5694/mja2.52593.

1. Supplementary methods: the Hope for Health Program (study intervention)

Co-design and development: Hope for Heath started in an informal way through long established relationships between two Balanda (non-Indingeous) long term residents (Timothy Trudgen and Dr Kama Mico) and Yolnu women (Dianne Birritjalawuy, Joanne Garngulkpuy, and Dorothy Bebuka). The balanda couple initially supported Ms Biritjalawuy as a friend in a health crisis to make dramatic changes in her diet. The resulting transformation inspired other Yolnu women in the community to seek help. These two balanda professional's had training in health, anthropology, and working knowledge of the Yolngu language, and over a decade of experience in crosscultural community work and education.

These informal engagements developed into close partnership with 12 Yolnu women involving an inter-cultural exploration of the chronic disease crisis and nutrition knowledge, establishing a local steering committee, and trialling intervention models based on the committee's discoveries and preferences. The co-designing of the program, utilised an adaption of the "enterprise facilitation" method (1) and a participartory community development approach. It was not an academic exercise, but a practical, grass-roots, and cross-cultural process, focused on impacting the personally present realities of debilitating health, and dying friends and family.

The pre-existing relationships of the group mutually held great value in the significance of local Indigenous knowledge. So as the program was formalised primary emphasis was placed on recognising and building foundations upon *Yolyu rom*, which refers to the laws, cultures, and ways of the people. This emphasis is assumed in the two arms of Hope for Health activities "marngikunhamirr"—to exchange and impart knowing—and "Gonnayathanhamirr"—to support, walk hand in hand.

The foundational role of Yolŋu traditional knowledge is most prominent in the content of the educational arm. This content was, and continues to be developed through a "two-way" world-veiw analysis approach called "Discovery Education" which has a history of use in Arnhem Land, but little academic exposure. (2) This approach emphasises understanding the themes that exist in the local language and culture that can be built on to reasonably explore and explain new knowledge. (3) It is recognised that in encountering the Western dominant culture, Yolŋu are are likely to have poor health literacy, (4) having been exposed to foods, lifestyles, and socioeconomic changes the consequences about which they did not understand. The Yolŋu committee with balanda partnerships through pilot programs developed an understanding of the health literacy confusions arising from modern change, along with the cultural concepts that could be used to fill these knowledge gaps.

Consequently, Hope for Health education starts the exploration of modern diet and disease though Yolŋu frameworks, their health history, food beliefs and categories. For example Yolŋu have two food groups, *Mathayal* and *Murn'yaŋ*. These consist of meat foods and plant foods respectively. Hope for Health uses 6 traditional Yolŋu food rules for eating and harvesting as a way to assess modern foods, make better food choices in the store, and eat based on satiation to manage energy intake. This requires an understanding of the ways in which Western processed foods have been changed compared to traditional foods. For example, exploration of the meaning of concepts like "nutrients" for understanding the advantages of fresh and traditional foods, involved starting with Yolŋu conceptualisation of "Daŋgi'yun" the tender care and breast feeding of a baby (5).

Nutrition education model: The "discovery education" led to the group identifying Yolnu traditional dietary ways as valuing a mix of animal foods and carbohydrate sources (mostly plants), and highly valuing sources of natural fats. The committe's emphasis strongly endorsed building local understanding of good foods based on this tradition emphasising unrefined, unprocessed, naturally grown foods that would help prevent and reduce the impact of diabetes. Thus, when incorporating western knowledge on nutrition, co-design favoured expertise endorsing whole foods, inclusion of meats, low carbohydrate remission models, (6) and reduction of processed store foods. Using this conceptualisation of the "good", was not to define or advise a set diet. The goal of "marngikunhamirr" is to provide the knowing, both intellectual and experiential, that the people need to make their own choices, whether that be in purchasing at a store or incorporating more traditional foods in their lifestyle.

"On-country" health retreat: Initial engagement and recruitment to the program is focused on the opportunity to attend a 12 day camp near traditional hunting and harvesting country. The purpose is to create a space for people to learn deeply about how to improve their health and experience the benefits of eating well, living well, and stopping smoking. A doctor and/or nurse attends to monitor health in individuals with comorbidities. Participants are then provided with ongoing access to a Health Coach's advice and Health Coaching group activities for the rest of the 16 week program (Figure 1). People who did not attend the retreat (historically 20% of those who sign-up) receive catch-up at home Health Coaching and all other Hope for Health group activities.

Health coaching: Health Coaching is the English terminology for activities related to the larger goal of "Goŋ-ŋayathanhamirr," the coming alongside each other to support progress towards wellbeing goals. It incorporates learning, but focuses on support to overcome challenges. Practically this includes both individual consulations with a trained "Health Coach" and peer group events such as family workshops, hunting trips, shop tours, ground ovens, and various cooking classes. This component of the Hope for Health program is intended to give participants easy access to health coaches and support all participants through the length of the program to help them integrate self-managed lifestyle change into their everyday life.

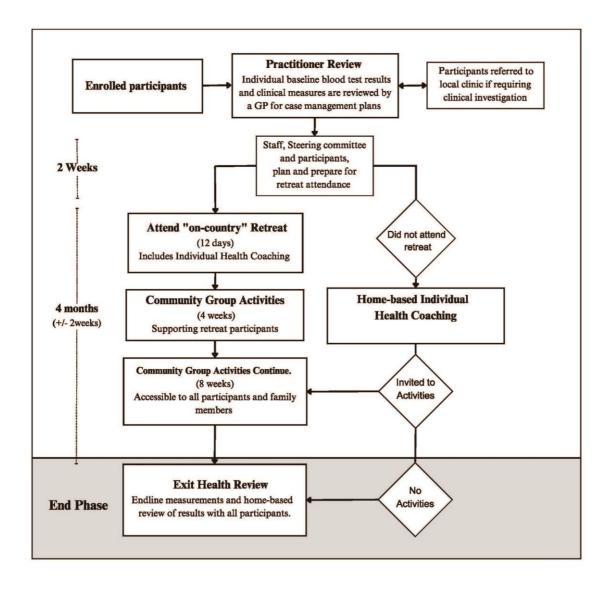
Individual health coaching sessions: These were held with participants in 2022, either while at the retreat, or via home-based visits for those that did not attend the retreat, (Figure 1). All individual Health Coaching sessions are similar to the home-based visits described below, except the supporting education in home-based visits was provided as videos, instead of during the retreat. Participants were aware that they would have the opportunity to see the changes in their results at the end of the 4-month program and discuss their progress.

The home-based health coaching visits involved the following elements:

- 1. Discussion of the participants existing knowledge and goals.
- 2. A detailed explanation of metabolic disease and risk indicators in their baseline measurements.
- 3. Exploration of how their results and measurements affected their health goals and any questions relevant to these results.
- 4. The participants watched and discussed two videos in Yolnu Matha (each 20 min long) covering foundational information on causes and prevention of chronic disease, focusing on diet and smoking. Further information and advice was given on the basis of participants queries and interest.
- 5. Visiting the clinic was encouraged for any relevant health concerns and the integration of clinic health checks and medications for disease management was discussed and encouraged.
- 6. Attending Health Coaches were qualified nutritionists, new to working in Arnhem Land. They were trained over 6 weeks in the Hope for Health approach and methods, cross-cultural skills, and motivational interviewing. They attended to participants with local Yolnu staff whenever they were available.

Engagement with Hope for Health: Hope for Health staff endeavoured to keep in touch and to inform participants of groups sessions and event schedules but participants had to attend on their own effort or request pick up by vehicle. Hope for Health allows paptricipants to engage within clear boundaries but does not require participation, as is the Yolŋu way. People recruited to the program could decline any of the elements of the program, and all participants and their families continued to have access to the program, regardless of degree of engagement.

Figure 1. 2022 Hope for Health participant flow



2. Supplementary methods: recruitment and assessments

Community input into research process:

- 1. Presentations to key community groups: Miwatj Health Aboriginal Corporation, The Arnhem Land Progress Aboriginal Corporation, Local Shire Authority, and Yalu Aboriginal Corporation, all provided feedback on the project.
- 2. Sensitisation was carried out before project commencement to provide general information about the proposed research study to the local elders, community members, health personnel at the local health clinics and other stakeholders (eg stores, school), which gave time for understanding, discussion and feedback about the proposed program and research
- 3. A study advisory committee was set up with the local research team, local chief investigators to guide the implementation of the study.
- 4. A 5-day co-design event was conducted in the community during which the research team and many invitees from the community participated (see below).

Integration and training of Yolyu research staff: The local research team, Yolyu steering committee, and invited community members participated in one week of workshops prior to recruitment, where information from Investigators and content experts was shared with translation to Yolyu Matha. Plans, messaging, questionnaires, and procedures were refined with Yolyu and approved for delivery in the local Indigenous context. On the job training, feedback, and support regarding research methodology and procedures was provided continuously by the research officer who resided in the community for the duration of the project.

Recruitment: The Hope for Health program was advertised within the community through information flyers, community events and the community loudspeaker. Four field teams each consisting of one local researcher, one Hope for Health member and the research officer or research co-ordinator visited all households in the community to provide information about the Hope for Health program and the research study. Individuals within the 18–65 year age range were invited to register their interest and gave permission for clinicians to review medical records for inclusion and exclusion criteria.

Enrolment: Individuals who were assessed as potentially eligible on medical record screening, were then invited to attend a clinic visit where the research team discussed the study with prospective participants in English and Yolnu Matha using the Participant Information and Consent Forms. All participants provided written informed consent. Eligibility was confirmed and participants undertook baseline measurements. Hope for Health usually takes participants to the local clinic for adult health checks prior to commencing the program. In 2022, the researchers undertook these checks as part of baseline measurements in conjuction with doctors at the local clinic.

Additional detail on blood pressure measurements: a single blood pressure measurement was taken in a sitting position by trained personnel. Measurements were taken 30 minutes after participants arrived in the clinic, therefore in a resting state.

Additional detail on blood biomarkers of metabolic health and inflammation: standard operating procedures were followed for collection, processing, storage and shipment of bood. Briefly, venous blood smaples in nonfasting participants were collected by a trained nurse or clinician. Upon collection serum and EDTA tubes were centrifuged and placed in the 4°C fridge ready for collection through routine Miwatj channels (Western Diagnostic Pathology).

Cultural compatibility: Each "on country" retreat accommodated at most 34 individuals. With a planned sample size of 66, two consecutive traditional retreats were held. The Hope for Health Steering Committee checked for cultural compatibility and allocated Yolnu participants to either the first retreat or second retreat in the three weeks prior to program commencement. This grouping was based on any participant preferences communicated to the research team and known family connections to ensure there was minimal cultural conflict within the retreat groups. This is essential in communities living according to traditional kinship rules.

Capturing and eliciting adverse event/reaction information: Adverse events and adverse reactions (non-serious and serious) were captured from the time of commencement of the Hope for Health program until conclusion of the program and all events were followed until resolution or stabilisation. Participants were asked "How have you felt since your last visit?" in order to elicit any medically related changes in their well-being. They were also asked if they had been hospitalised, had any accidents, used any new medication or changed concomitant medication regimens.

Safety monitoring: Safety oversight was under the direction of a Data Safety Monitoring Board. The board was made up of an independent clinician, a statistician and an Australian Aboriginal academic, who, collectively, have experience in the management of adult patients, biostatistics and the conduct and monitoring of studies in Indigenous communities. Members of the Data and Safety Monitoring Board were independent of study conduct.

Study feedback to community: Individual results were given to participants at the time of the endline assessment and these provided basis for health coaching and advice for the future. As well, the study co-ordinator returned to the community in June/July 2023 to check in with participants and communicate the overall study findings for each individual (eg changes in weight, HbA1c and lipids); 80% of the participants were able to be contacted for this purpose. As well, the summary results were presented to the study advisory committee and the Hope for Health Yolnu Steering Committee (March 2023). The study co-ordinator, principal investigator and local chief investigators also presented the study results to community stakeholders which included community elders, local health clinics, The Arnhem Land Progress Aboriginal Corporation, local/shire authority, and in numerous yarning circles during July—November 2023.

3. Re-lighting the fires: a Yolqu-led evaluation of Hope for Health program

A Yolnu understanding of 'health' emerging from the evaluation (37 participants) and the guidance of the Yolnu chief investigator [J Dhurrkay] depends upon the interconnectedness of peoples, places, and histories.

Methodology: At the suggestion of the chief Yolnu evaluators, the epistemic basis and criteria for evaluating the Hope for Health program and retreat were the five steps of a 'Methodology for Yolnu Research'.(7)

- lundu-nhina properly interconnected in place
- rom-lakaranhamirri reminding each other of traditional ways of doing things
- rälmirriyanhamirri sharing the tasks to be done
- räl-gäma bringing back what we must share
- rulandhuna putting what we have produced in place for sharing

The methodology grounds a Yolŋu vision of traditional understandings of health and diet. It reveals consistencies of the retreat with this vision. It also reveals where changes could be made to bring Hope for Health programs into closer alignment with Yolŋu understandings of health, and means for constituting healthy Yolŋu people-places.

Results: Factors contributing to Yolnu health:

- The food we eat, as well as the places where we procure, prepare, consume, and share with kin, and the physical activities which finding and preparing food entails fundamentally contribute to health.
- Yolnu healthy minds and bodies also arise from knowing that different foods belong to different clan groups, that food has kinship, and is sung and cried in ancestral songs, and represented in dance and painting.
- Being in the environment is fundamental to Yolnu health: feeling the strength and direction of breezes, understanding what flowers and fruits are available day to day and how they give us signs of the seasons and what foods are available.
- The generous sharing of food, and the telling of stories of where the food comes from, who it belongs to and how skilfully it was produced all contribute to Yolnu health. Health is about knowing both who, and where, you are.

<u>Results:</u> Through the processes of evaluation, there was endorsement of agreed processes by which Hope for Health programs could continue to integrate traditional Yolnu understandings of food and wellbeing. These include:

- Focusing retreats on the traditional practice of wakir'yun: an extended family group out bush or beach for a few days, sharing and making health and wellbeing together.
- Remembering the importance of fires (and relighting the fires) dhanalkum: Yolnu being together, eating cooking and talking together, and being properly in place together.
- More inclusion of ceremonial work (singing, dancing etc) in Hope for Health programs to connect people to their creators
- Elders singing milkarri (women's crying songs) while food is being prepared to remember the connections of foods to clan groups and creators.
- Remembering and reminding people about how foods have kinship and connect them to ancestral songs, stories, peoples and places.
- Remembering and reminding that Yolnu food has its own 'policy' i.e. as you eat it, you know what's right and wrong for you. You are rumbal-watanu (in charge of you own body) but also nayanu-watanu (in charge of your feelings). For example, your body knows how much it can take, e.g. turtle fat, you don't eat too much. (This in contrast to the many bad foods from the store that you can't say no to they are full of flavour dhäkay but that's all.)
- Remembering the Balanda (non-Indigenous) medical stories about the great importance of white and red blood cells and bones make the same point as the Yolnu understanding of the sacred nature of bones and blood. They work together.

Quote from one 2022 Hope for Health on-country retreat participant

I'm going to tell you about Hope for Health program - very good for you and me. For body, make heart good, drop your weight. First my story is that I was wondering what is it and they gave us lovely food and I ate it. I thought I will join the program and now here I am... I came from Elcho with a heavy body and feeling sick, weight 110, came here, sat down ate good food, salad, and walked around and it's helping me to lose weight. And nice food, good blood, we are become heathy - cleaning inside our body. I was eating lots of sugar, and now I drink lots of water and feeling healthy, Here [name] and I, every morning go for a walk, exercise for our body, it's good, helpful, you hear the story of ill health. And good food will return to what we used to eat long ago, not strange food but bush food, but this Balanda food – salad is good, energy, but no sugar. Its big name is sugar but it comes in all forms, it makes you fat and heart attack or stroke, and you need injections. And tobacco, mixed, heart attack, can you see this?

4. Supplementary results

Table 1. Numbers of participants in the 2022 Hope for Health program and research evaluation, by program element

| Element | Key elements | Number |
|-------------------------|---|--------------|
| Research element | Participants registered and consented to health screening | 177 |
| Research element | Potentially eligibile for the Hope for Health program and study | 138/177(78%) |
| Research element | Eligible and consented to Hope for Health program and study | 66/138 (48%) |
| Research element | Completed baseline measurments | 66/66 (100%) |
| Hope for Health element | Practitioner review | 66/66 (100%) |
| Hope for Health element | Attend on country retreat | 14/66 (20%) |
| Hope for Health element | Attended home-based or individual health coaching* | 56/66 (85%) |
| Hope for Health element | Attended community group activities | 19/66 (29%) |
| Hope for Health element | Did not participate in any Hope for Health activities | 10/66 (15%) |
| Research element | Completed primary outcome measurements | 56/66 (85%) |
| Research element | Completed other endline measurements | 54/66 (82%) |

^{*} Fourteen participants received individual health coaching at the retreat.

Table 2. Reasons for not attending on country retreat*

| Reason | Number |
|--|--------|
| No longer interested/disengaged | 6 |
| Looking after kids/family | 15 |
| Attending ceremony (funerals) | 9 |
| Unwell | 2 |
| Away from community | 17 |
| Work commitments | 6 |
| Stress/anxiety about family | 2 |
| Family member did not want participant to attend | 2 |
| Not enough clothes to attend | 1 |
| Multiple engagements not specified | 1 |
| Could not contact or loss to follow-up | 7 |

^{*} Multiple reasons possible.

Table 3. Hospitalisations, clinic visits, and changes in medication after baseline*

| Characteristic | Number |
|---|--------|
| Hospitalisation: reasons [†] | 4/53 |
| Domestic problems | 2/4 |
| Treatment of sleep apnoea | 1/4 |
| Bladder issues | 1/4 |
| Attended clinic: reasons | 23/53 |
| Health check-up | 17/23 |
| Collect medication | 6/23 |
| Liver check | 1/23 |
| Check for blood sugar and blood pressure | 1/23 |
| No reason given | 1/23 |
| Change in medication since baseline | 7/53 |
| Glycerol trinitrate, metoprolol tartrate, rosuvastatin and ramipril stopped | 1/7 |
| Iron supplementation | 2/7 |
| Paracetamol | 1/7 |
| Antibiotics | 1/7 |
| Liver medication | 1/7 |
| Medication for fat/cholesterol | 1/7 |

^{*} Two participants declined the questionnaire; multiple responses possible.
† Gove District Hospital (Nhulunbuy) or Royal Darwin Hospital (Darwin), Northern Territory.

Table 4. Anthropometry and metabolic outcomes at baseline and endline: intention-to-treat analysis (66 enrolled participants)

| Outcome | Participants: baseline/ study end | Baseline | Study end | Mean change (95% CI) |
|---|---|------------------|------------------|------------------------|
| Anthropometry | | | | |
| Weight (kg), mean (SD) | 66/55 | 84.5 (18.4) | 83.6 (17.0) | -1.46 (-2.41 to -0.51) |
| Body mass index (kg/m²), mean (SD) | 66/53 | 30.3 (5.4) | 30.0 (5.2) | -0.59 (-0.92 to -0.26) |
| Waist circumference (cm), mean (SD) | 66/53 | 108.6 (12.5) | 105.7 (11.5) | -3.16 (-4.68 to -1.63) |
| Blood pressure | | | | |
| Systolic (mmHg), mean (SD) | 66/52 | 131.4 (16.5) | 131.1 (19.0) | -0.75 (-4.53 to 3.04) |
| Diastolic (mmHg), mean (SD) | 66/52 | 81.2 (11.6) | 79.4 (12.8) | -1.86 (-4.19 to 0.47) |
| Biomarkers | | | | |
| C-reactive protein (mg/L), median (IQR)* | 64/46 | 8.5 (4.0–13.0) | 9.0 (4.0–14.0) | 0.97 (0.76 to 1.24) |
| HbA _{1c} (mmol/mol), median (IQR)* | 66/50 | 41.0 (37.0–51.0) | 39.0 (34.0–44.0) | 0.89 (0.85 to 0.93) |
| Cholesterol (mmol/L), mean (SD) | 66/50 | 4.9 (1.1) | 4.8 (1.6) | -0.01 (-0.30 to 0.29) |
| Triglycerides (mmol/L), median (IQR)* | 66/50 | 2.4 (1.6–3.5) | 2.5 (1.8–4.0) | 1.08 (0.92 to 1.25) |
| HDL-cholesterol (mmol/L), mean (SD) | 66/49 | 0.9 (0.2) | 1.0 (0.2) | 0.06 (0.00 to 0.11) |
| LDL-cholesterol (mmol/L), mean (SD) | 59/40 | 2.7 (0.9) | 2.5 (0.9) | -0.28 (-0.47 to -0.08) |
| Cholesterol ratio, mean (SD) | 66/49 | 5.5 (1.3) | 5.0 (1.5) | -0.45 (-0.84 to -0.07) |

CI = confidence interval; HbA1c = glycated haemoglobin; HDL = high-density lipoprotein; IQR= interquartile range; LDL = low-density lipoprotein; SD = standard deviation.

* Change reported as geometric mean ratio (ie, relative change in geometric mean).

Table 5a. Adverse events during the retreat component of the study

| Adverse events | Total |
|---|-------|
| Participants | 14 |
| Adverse events* | 8 |
| Participants with at least one adverse events | 4 |
| Probable intervention-related adverse events | 3 |
| Participants with at least one probable intervention-related adverse events | 2 |
| Serious adverse events | 0 |
| Participants with at least one adverse events | 0 |
| Intervention-related serious adverse events | 0 |
| Participants with at least one intervention-related serious adverse event | 0 |
| Participants with at least one hospitalisation | 0 |
| Participants who died | 0 |

^{*} Includes serious adverse events.

Table 5b. Individual events for participants with at least one adverse event during the retreat

| Participant ID | Diagnosis or symptoms | Date of onset | Severity | Relationship to intervention | Outcome |
|-------------------|-------------------------|------------------|----------|------------------------------------|----------|
| 067 | Chest infection | Prior to retreat | Moderate | Unrelated | Resolved |
| 067 | Cough | Prior to retreat | Moderate | Unrelated | Resolved |
| 063 | Thrush | Prior to retreat | Moderate | Unrelated | Resolved |
| 063 | Urinary tract infection | Prior to retreat | Moderate | Unrelated | Resolved |
| 007 | Bloating | Unknown | Mild | Probable | Resolved |
| 007 | Earache | Unknown | Mild | Unrelated | Resolved |
| 007 | Back ache | Unknown | Mild | Probable | Resolved |
| 005 | Headache | Unknown | Mild | Probable | Resolved |

5. References

- Sirolli E. Ripples from the Zambezi: passion, entrepreneurship, and the rebirth of local economies. Gabriola Island, B.C.: New Society Publishers, 1999.
- 2. Shield JM, Kearns TM, Garngulkpuy J, et al. Cross-cultural, Aboriginal language, discovery education for health literacy and informed consent in a remote Aboriginal community in the Northern Territory, Australia. Trop Med Infect Dis 2018; 3: 15.
- 3. Vass A, Mitchell A, Dhurrkay Y. Health literacy and Australian Indigenous peoples: an analysis of the role of language and worldview. Health Promot J Austr 2011; 22: 33-37.
- 4. Rheault H, Coyer F, Jones L, Bonner A. Health literacy in Indigenous people with chronic disease living in remote Australia. BMC Health Serv Res 2019; 19: 523.
- 5. Why Warriors Org Ltd. Chronic disease 2, nutrients, energy & fuel from food. Djambatjmarram: our Yolngu YouTube channel; 19 Nov 2022. https://www.youtube.com/watch?v=SQmpEDFFRy4&t=545s (viewed Mar 2024).
- 6. Unwin D, Delon C, Unwin J, et al. What predicts drug-free type 2 diabetes remission? Insights from an 8-year general practice service evaluation of a lower carbohydrate diet with weight loss. BMJ Nutr Prev Health 2023; 6: 46-55.
- 7. Läwurrpa E, Garngulkpuy J. Methodology for Yolnu research [draft document]. Charles Darwin University, 19 Apr 2005. https://digitalcollections.cdu.edu.au/nodes/view/7871 (viewed Aug 2024).