Hope for Health

Riyala Retreat April 2019

Evaluation Report

November 2019

Research Facilitation:
Joanne Garŋgulkpuy, Hope for Health

Report compiled by:
Michaela Spencer and Michael Christie**,** Northern Institute, Charles Darwin University
Sarah Hanieh and Beverly Biggs, Peter Doherty Institute for Immunity and Infection, University of Melbourne

HOPE FOR HEALTH ARNHEM LAND

THE UNIVERSITY OF MELBOURNE

CHARLES DARWIN UNIVERSITY
NORTHERN INSTITUTE
People. Policy. Place.

Contents

Acknowledgements

This report was commissioned by the Why Warriors Organisation and has been made possible through funding received from public and philanthropic sponsors, including Tear Australia and ALPA.

We are grateful to the following people for their contribution to the project (listed in alphabetical order):

Beverly-Ann Biggs, Department of Medicine at the Peter Doherty Institute for Immunity and Infection, University of Melbourne

Broc Martin, Hope for Health

Colin Baker, Hope for Health

Dianne Biritjalawuy, Hope for Health (Co-Founder)

Jane Bennett, Hope for Health and ArKipelago consulting

Joanne Garŋgulkpuy, Hope for Health

Kama Mico, Hope for Health (Co-Founder)

Kathy Guthadjaka, Hope for Health

Michael Christie, Northern Institute, Charles Darwin University

Michaela Spencer, Northern Institute, Charles Darwin University

Sarah Hanieh, Department of Medicine at the Peter Doherty Institute for Immunity and Infection, University of Melbourne

Wayne Munster, Hope for Health

Thanks also to all Hope for Health staff and participants involved in the April 2019 retreat, and to Miwatj Health for their cooperation and support around data collection and sharing.

Key Insights and Findings

Ground Up Research

- Participants described being excited and energised by the experience of the retreat. Elements involving traditional food gathering and preparation techniques were highly valued, and there was novelty and interest associated with measurements of weight and blood sugar.
- There were some feelings of sorrow and frustration associated with learning that many Balanda foods (incl. traditional mission foods) were unhealthy and to be avoided, and that Yolŋu had not been told this previously.
- Those who describe being most impacted by the retreat often had clear reasons for attending (e.g. identified medical issue, or family recommendation).
- By the end of the retreat, most of the Yolŋu participants that we spoke to had clear understandings of biomedical relations between diet and health (e.g. causal relationships between food types and medical conditions).
- When returning home, many experienced it as possible to maintain practices of healthy eating when they could control their own meals. However, they found this more challenging at times when they were reliant on family members to provide or supplement their meals.
- A key outcome for many of the retreat participants was an interest in teaching their new understandings and health practices to their children and grandchildren.
- It was clearly articulated by many, that maintaining practices of healthy eating at home in Galiwin'ku and with children around was a valued aspect of the program that was also important to its ongoing life and success going forward.
- In describing the potential for success over time, many pointed to social factors – beyond food alone – as important health work. This includes building community through Hope for Health staff, visiting people, sitting and talking and cleaning the house together, as well as revisiting possibilities for gardens, farms or forms of food-based industry in Galiwin'ku.

Biomedical Research

- When assessing the results of only first-time participants:
    - There was a large reduction in weight, and waist circumference;
    - A moderate reduction in prevalence of elevated HbA1c and blood pressure from baseline until 3 months follow up.
- When considering the total participants
    - There was a significant weight loss amongst participants from baseline to the end of the two-week retreat, and a trend towards weight loss when comparing baseline weight with weight at the three-month follow up.

- Mean waist circumference significantly decreased in participants from baseline to the end of the retreat and this was maintained at the three months follow up.
- There was a trend towards a decrease in mean body mass index from pre-retreat to post-retreat, however this did not reach statistical significance.
- There was no change in mean blood pressure from pre-retreat to 3 months post-retreat
- There was no change in mean HbA1c levels or proportion of participants with elevated HbA1C levels from pre-retreat to post-retreat.
- There was no change in mean cholesterol or lipid concentrations when comparing pre-retreat to post-retreat measurements.

Executive Summary

Ground Up team at the Northern Institute, Charles Darwin University, and researchers from the Peter Doherty Institute for Immunity and Infection, University of Melbourne, have been engaged by the Why Warriors Organisation to help them evaluate the delivery of their Hope for Health retreat for Yolŋu participants in Riyala, Darwin in April 2019.

Hope for Health draws on both Yolŋu and Western understandings of health, knowledge of foods and cooking. The Riyala retreat was the latest in a series of retreats facilitated by Hope for Health. It lasted for 14 days and was attended by a group of 30 Yolŋu participants, including Hope for Health Yolŋu board members and staff.

Participants at the retreat followed a daily routine that supported an intensive learning and exposure to a healthy diet, exercise and health care support. The program included an initial 3-day juice fast, then regular high fat, low carb meals as well as a range of activities (e.g. exercise, lectures, bush food preparation, painting and dancing) as well as access to on-site doctors and a range of health practitioners (e.g. naturopaths and massage therapists)

The purpose of the evaluation has been to draw on different methods of data collection and evaluation research in engaging with the program, assessing its impact and supporting future activities.

- The Ground Up team, CDU, worked collaboratively with Joanne Garŋgulkpuy (local researcher and Hope for Health Board member) to develop ways to understand and record Yolŋu experiences of the retreat, including what counts as good health and how it can be maintained.
- The team from the Peter Doherty Institute, Melbourne University carried out biomedical assessments before, during and after the retreat, to assess the impact of changes in diet and eating practices on participants.

Both these threads of evaluation appear in this report. The Ground Up approach, included details of the development of an evaluation tool, are presented in Part 1. Results and analysis of the biomedical testing are provided in Part 2. Results of both these approaches are then drawn together in a final Discussion section, which addresses the TEAR evaluation requirements.

Visible across both forms of evaluation research, was the sense that the retreat was experienced positively by participants, and that it had a considerable impact on their eating practices, weight and sense of well-being. Also clear were many of the challenges faced by participants in seeking to make long term changes within their eating habits and lifestyles when returning to Galiwin'ku, even while many recognised health and well-being as complicated and long-term undertaking, involving sustained intergenerational community and cultural maintenance work.

The active presence of a local coordinator, and Yolŋu Hope for Health staff, was seen as a crucial support for participants seeking to develop and maintain changed practices around health and eating

over time. The local coordinator was trusted and appreciated. The on-ground and in-community element of the program was recognised as able to connect in with the practices, interests and challenges of everyday life in community, and as able to support interests in maintaining Yolŋu practises of hunting and food preparation.

Amongst many of the senior women involved in the program, the maintenance of Yolŋu knowledge and practices of food gathering and preparation at home, in Galiwin'ku, was seen as the key to better possibilities for health and well-being for young people, and the generations to follow. Many Yolŋu struggles with health, are also to do with struggles with new foods which are not accompanied by their own particular stories, detailing how they should be collected and prepared, and to whom they belong. These new foods are disconnected from seasonal weather changes and hunting practices, and remain consistent within the shop all year round.

Within the biomedical research, it was difficult to draw strong statistical claims given the sample size of the retreat cohort. However, the most significant impact of the retreat was on the weight and waist circumference of participants. These dropped significantly at first, and were, to some extent sustained over time. Many of the participants expressed interest and excitement at being able to be told their 'numbers', as a way to measure change and progress in their health and as a way to engage with doctors around existing or likely health issues.

The Ground Up research suggested that there was not only one understanding of 'health' present within the program, but rather it was useful to think of several interrelated stories of health which were all significant to participants' experiences, and which all needed to be attended to if change was to be slowly and sustainably made. Indeed, carefully making sure that not one of these stories gained priority over the others was a crucial component to assisting the program and its activities to remain strong.

However, there was an emerging concern amongst many members, that what was most important was that all stories of health come together and interrelate in place – that is in Galiwin'ku community. It was recognised that health was not something separate to living well on-country, and developing ways to remember and maintain ancestral Yolŋu knowledge while also living in a contemporary setting and its many challenges.

Beyond engaging with participants of the retreat, and carrying out evaluation research, another outcome of this work has been the development of a Ground Up/quantitative evaluation tool. This tool could be used by retreat staff or others to assist monitoring and evaluation of future retreats or ongoing program work. It relies on face-to-face discussions/story-telling and the collecting and analysis of participants' responses. Further details of the tool and its potential use are provided at the end of Part 1 of this report.

Hope for Health staff discussing the program during initial consultations at Galawarra

Part 1:

Ground Up Research

Ground Up

Background

Ground Up is an approach to research and service delivery that develops tools, methods, understandings and practices appropriate for the people, places and organisations with whom we work. This involves working collaboratively on the ground, taking seriously the knowledge and governance of both Aboriginal and non-Aboriginal people. Research and evaluation involves participating in the collective life of particular places, and doing so in collaboration with local researchers and consultants who belong to that place or organisation.

GroundUp research and evaluation methods take seriously at the outset, the authority and sovereignty of Aboriginal knowledge authorities and elders and their various places, and work collaboratively with them to design, undertake and evaluate research and service delivery from the ground up. Interpretive work – where possible – engages both traditional Aboriginal knowledge and agreement making practices, and those of government and nongovernment organisations, and universities.

The guidance of Joanne Garŋgulkpuy (www.cdu.edu.au/centres/yaci/consultants_joanne.html), an experienced Yolŋu researcher and Hope for Health Steering Committee member, was central to the planning and conduct of the evaluation. Throughout the process she has provided assistance around the research approach, research questions and bilingual facilitation of research interviews. As well as the interpretation and presentation of results.

The evaluation project has also been significantly aided by the support of Kama Mico (Hope for Health, Co-founder and Program Manager) who facilitated meetings with Steering Committee members and staff in both Darwin and Galiwin'ku, and assisted with all stages of the research process.

Aims and methods

We started with discussions and storytelling from Hope for Health Steering Committee members. These initial discussions helped us to develop a set of concepts, or 'Stories of Health', which emerged in these discussions. These differing 'Stories of Health' have offered a way to read, collate and interpret the experiences of retreat participants, and track or assess future developments. We also see these stories as offering a basis for potential further M&E work that could be closely integrated within the ongoing practice of the Hope for Health program.

The second phase of the research involved discussions with Hope for Health participants at the beginning, and end, of the Riyala retreat.

Phase 1: Steering Committee discussions

In Darwin

- Meeting 1: With Dianne Biritjalawuy, Kathy Guthadjaka, Colin Baker, Kama Mico and Michaela Spencer on 1 Feb 2019 to learn about Hope for Health.

- Meeting 2: With Dianne Biritjalawuy, Kama Mico and Michaela Spencer on 8 Feb 2019 about the origins of Hope for Health and Biritjalawuy's story.

At Galiwin'ku

- Meeting 3: With Steering Committee members as part of a hunting trip at Galawarra on 16 Feb 2019
- Meeting 4: With Hope for Health staff as part of a hunting trip at Galawarra on 16 Feb 2019
- Meeting 5: A follow-up meeting between Garŋgulkpuy and Michaela was held on 17 Feb 2019

In Darwin

- Meeting 6: A final meeting between Kama and Michaela took place in Darwin prior to the retreat on 26 March 2019

Phase 2: Discussions with Retreat Participants

Two visits were made by Michaela to the Riyala retreat, where she worked with Joanne Garŋgulkpuy initiating interviews with participants.

At the Retreat

- Day 1: Introduce the evaluation and to work with Garŋgulkpuy to interview participants. Participants were interviewed in small family groups, with 6 group interviews taking place and 17 people offering initial thoughts and reflections.
- Day 12: Work with Garŋgulkpuy to interview participants in small family groups. 7 group interviews were conducted, with 14 people offering their reflections on the retreat.
- During the retreat morning walks, brief comments and reflections were also recorded by Broc Martin (Health Coach Mentor, Hope for Health).

3-month follow up

- Three months after the retreat, Michaela returned to Galiwin'ku, spoke to many of the participants of the retreat. This meeting was aided by Broc Martin (Health Coach Mentor, Hope for Health) who facilitated a hunting trip and dinner on Mission Beach, Galiwin'ku. 14 participants from the retreat attended this meeting.

Developing an evaluation toolkit

The 'stories of health' that appear in this report, offer the basis for an 'evaluation tool' which is mobilised in the evaluation of the retreat, and outlined in simple terms in Part 3 of this report.

This tool offers a set of evaluation questions, and draws on these stories as a basis for interpreting and assessing interview responses. This demonstrates outcomes of the program as emerging in a context of complex and inter-cultural ways of constituting health and well-being.

Many stories of health

In speaking with Yolŋu members of Hope for Health, there were complex, interconnected narratives of relationships and circumstances of those relationships that emerged in their discussions.

Below we cluster these accounts to reveal several prominent stories of health and wellbeing that are present within Galiwin'ku, and the Hope for Health program. These stories are not always consistent with each other, and sometimes present quite different logics around what health is and how it may be achieved.

All of these stories can be discerned in the accounts of Hope for Health provided by Steering Committee members, staff and participants. They form part of the complex bundle of practices supported by hope for Health, and being navigated by those involved.

STORY 1: "Feeling Different" – Biomedical Story of Personal Health

'I can feel sugar level down, blood pressure, everything'

Some of the Yolŋu involved in Hope for Health, have experienced dramatic and very visible medical benefits in very short spaces of time. These experiences are often described in terms of feelings in the body and levels of activity that they are able to achieve.

> *Before I was in a wheelchair. I was covered in boils that weren't getting better. So unwell. No walking, just taking 3, 4, 5 steps and puffing. After 3 weeks testing it out [new diet] I took my niece to preschool, and went back in the afternoon to get her. Up and down the big hill. I think it was like miracle - Dianne Biritjalawuy, SC Member*

> *I was different after 3 weeks, after a month. I had a different feeling. It was different food, different taste. I was learning some new ways, how to cook good food. Then after one month there was a change, [I was] different. Walking down the hill, bringing my kid my niece back from school. Taking her to school in the morning. I could do these things now - Dianne Biritjalawuy, SC Member*

The biomedical aspects of health change and health monitoring can be intriguing and exciting for those experiencing them, with changes in food also becoming reflected in greater levels of control over medicine and interest in ways of measuring biomedical effects.

> *We're trying to find the path together. Learning about food, and also medication. Learning to have control of that [medicine] yourself – Steering Committee Member*

> *We always go there [doctor's] for check-up. We've been to naturopath. The way they help us was exciting. They [participants] were very excited. Everyone was trying their best with diet, and blood sugar going down. And hopefully for Year 2, we go back and it will still be better. They were teaching us, gave guidelines to help us keep going – Steering Committee Member*

Medical tests can offer clear stories and measurements that connect new understandings of food and ingredients with clear and visible medical effects. This in turn also supports the stories that participants are sharing with their families.

> *Children running with can of coke, bottle of coke. Not a good drink. Drink water, good for your body – Staff Member*

> *I always talk to my children. If you eat too much ŋatha (carbohydrates), you'll get sick. End up on dialysis. Eat fresh food, bush food. Often diabetes, sickness, is coming. No good. I can feel sugar level down, blood pressure, everything. As soon as we did that retreat, the medication went down automatically – Staff Member*

STORY 2: "Sharing Health" – Story of Creating a Healthy Community

'We are keeping the conversation happening, circling in the community'

The interviews revealed that Hope for Health also extends beyond individual experience. Developing new understandings and practices also helps to build community. Part of helping this to happen, is keeping the story of health alive in ways that make sense to Yolŋu and can activate change in others.

> *Sometimes if Yolŋu look from the outside, they might talk, talk, and no result. No education, no outcome or result. But we invite them to partake in it and experience it for themselves and see that result. And once they taste something here, and they go back, that story is circulating in the community. It's a small community, story gets around fast - Dianne Biritjalawuy, SC Member*

> *We're still here, making sure the [story of Hope for Health] is staying here. Because we have seen services like that coming out [and going away again]. We are keeping the conversation happening, circling in the community. People still ask about my story, I share with them. I am happy to share my experience, because it is the only way you will understand, feel – Dianne Biritjalawuy, SC Member*

> *So I can have something change. Inside. Be strong. Finish. The name of that is 'Hope'; for my people and for those that surround. The service providers, family, community and everyone – Steering Committee Member.*

The reason for spreading the word, and building community, is to benefit the young people. Helping them to learn about good and bad foods, and being able to learn about cooking and living together in good ways, for now and into the future.

> *This new story of healthy foods is also about having children involved with all these people. Like yesterday when we were cooking on the beach, and those young children were there as well. They were learning about the cooking and everyone was there altogether – Joanne Garŋgulkpuy, SC Member*

We have been teaching people this story, even our own kids. Telling story how to make stew, at the basketball court. Serving free one. There were lots of people coming in. All the kids go into the shop and get all the sweet stuff. Children running with can of coke, bottle of coke. Yaka good drink. Drink water, good for your body – Staff Member

Children eat foods from the shop, drink coke, and form gangs (like the graffiti on the demountable outside the women's centre – which is the name of an American gang). With Coke there is gangs, American culture, rap (not all rap is bad, that Baker Boy raps in Yolŋu matha (language) which is good. But it's not all like that). Changes are happening in the culture, the children are making their own way – Joanne Garŋgulkpuy, SC Member

Finding ways to keep the stories circulating is important Hope for Health work, and there are ways of maintaining regular events, and beginning to set up permanent spaces in Galiwin'ku that will help this work to continue.

We do cooking class every Thursday. We go out to woman's centre and have cooking classes. At the same time telling them story. All the vegetables you can buy that are good. Telling them that story. Tuesday cooking, every Tuesday we are cooking on Tuesday. Everyone comes. Kids. Serving everyone – Hope for Health, Staff Member

We are trying to… that we are trying to get a space, a building. Build something create a clear space. A space where people will come and go, share and take something back and start something outside. There is a place where you can come or there is a way you can take, follow that course – Dianne Biritjalawuy, SC Member

STORY 3: "Yolŋu Food Story" – The Yolŋu Story of Traditional Foods, Body and Place

'Two types of foods coming together, bush food and balanda food'

The work of Hope for Health, and the journeys of participants, exist at the intersection of balanda and Yolŋu foods, and food traditions. Finding better ways to manage this interface, and to balance these foods, can be exciting and empowering.

I was hearing about those traditional foods all over the world, and it helped me think about my own culture, and food and cooking. It helped me to explore. I was getting hungry for more stories and knowledge – Dianne Biritjalawuy, SC Member

Balanda didn't tell us about food, didn't let us know about shopping and health. It's good to go hunting. Balanda didn't know what was in the bush, only what is in the supermarket – Steering Committee

You know, one minute you are in the light, the next minute you are in the dark. Maybe it is like that. It is no good to blame, but it's a time when there is no balance. We are looking for ways to be balancing the two worlds – Dianne Biritjalawuy, SC Member

For Yolŋu traditional foods, there are clear directives that guide the times and the ways food must be prepared, and shared. These connect with ancestral knowledges, and are significant in maintaining laws and ways of relating to each other. In relation to balanda foods, these laws and relations that reveal what a food is and how it should be prepared and eaten, are not visible to Yolŋu (or others).

> *Every meat has law, and a way to go. You can't just cut it up in any way. Turtle, wallaby, fish, magpie goose all of these things have laws about how you prepare them. The songs are telling about the types of food that are edible for Yolŋu to eat and hunt for. Also there is a process for how we can cook the right way – Dianne Biritjalawuy and Joanne Garŋgulkpuy, SC Members*

> *The liver, traditionally, before, women weren't allowed to eat that liver. It used to be just men. If you go to Gäwa (homeland), you see a lot of young people who know how to cut it up. Cutting up respectful way. The hunter knows how to hunt and cut up and share with the others. When we go hunting turtle eggs there are 5 eggs shared with each family who was hunting – Dianne Biritjalawuy and Joanne Garŋgulkpuy, SC Members*

Yolŋu face challenges when navigating new foods, whose stories and ownership are elsewhere. These new foods not only make people unhealthy and unaware of what they are eating, they can separate Yolŋu from traditional practices and ways of living. Remembering and doing these traditional practices is part of what health 'is' for Yolŋu.

> *Healthiness, and being able to recognise that feeling of being healthy was always there before. Now there are new things around, the shop, gardens. Yams, cycads – carbohydrate bush foods were there, and these were healthy. More recently, our energy comes from damper, bread, sugar, tea. And was water too, would always have water and bush foods to satisfy myself. Matha-yal' and murnyaŋ' – these were two ways to classify foods. You would eat these different types of foods with different seasons. The food is still there to be collected, but today we are missing part of that, and we need to revisit – Joanne Garŋgulkpuy, SC Member*

> *Cooking at the beach today, the young ones were learning. We learnt from our mothers, we used to go with them bush hunting for yams. Now we are showing the other people, showing pathway, teaching the young generation so they never forget this way of cooking food – Staff Member*

STORY 4: "Retreat Story" – Story of the Retreat and its Effects

'Eyes were opened, new eyes – healthy'

There is a sense that the retreats offer a pathway to new knowledge and practices that can, in important ways, connect with Yolŋu places and cosmologies. The work of learning about and developing new connections around and through Western and Yolŋu practices of health can be difficult and create turbulence, but is also a good way to go.

Going into something new where we will find new health and new hope. We are entering into the new land. Riyala has been appointed for the retreat, but the journey started in Galiwin'ku – Dianne Biritjalawuy and Joanne Garŋgulkpuy, SC Members

For us to be healthy, there is a water that has to be flowing across our own body. It is flowing like a river. Firstly, the river has to flow [as starts to happen at the retreat]. Then there is a coming together of the salty and the fresh water [old habits and new]. Then it becomes calm as the salty and the fresh mingles together. This is happening at the retreat – Joanne Garŋgulkpuy, SC Member.

The retreats offer a way to introduce something new to people's lives. This change can produce negative experiences (particularly at the start) and may provoke critical responses from family and community members who are not involved in the retreat or interested in healthy living. This can create conflict, but some people choose to keep going.

Something new so we can know and that story of the new food, and the new pathway. Some people are still scared for this new food; saying everyone is sick from this retreat. But I don't know. They are already sick inside their body. The retreat is good – Steering Committee

Different, different kind of food at the retreat. Eyes were opened, new eyes – healthy – Steering Committee

First place, when came to retreat we were tired. By second day or third day we were happy. Getting up. Going hunting – Steering Committee

Just as important as the time away that the retreats provide, is the work on the ground in Galiwin'ku. Being healthy at home is the main priority for many, and the ongoing work done by Hope for Health staff in Galiwin'ku is crucial for this.

There has been a lot of work happening in the last little while, with those ladies who are staff members walking around, talking to people, taking the vehicle to drive around, getting purchase orders to buy food from the store and doing cooking classes/work once a week – Joanne Garŋgulkpuy, SC Member

There is scope for much more work – people making appointments with them, talking together about what food is healthy, what it does for the body, freedom for them to work this way. There is opportunity to give people the chance to be involved. Some people don't want to be in a 'program' but might just want to talk about other things – Joanne Garŋgulkpuy, SC Member

STORY 5: "Staying Healthy" – Story of Self-Discipline and Control

'The authority on the inside that you can do something'

For some people, their Hope for Health journey, started with the personal experience of witnessing significant change. Such as seeing the effect on Dianne Biritjalawuy when she started eating different

foods, and having a similar experience when they began to try similar practices themselves. This change was often described as an internal shift associated with both exercising, and experiencing the possibility of, greater levels of personal control.

> *I feel healthy, now it's not scary. It was scary before. That time before, we didn't know about these things. Hope for Health is a new story, new pathway. It was a miracle. I saw Biritjalawuy. She was sitting there. Eating new food – eggs, porridge. We started with that first. When I look back to that year, I see that's when self-control started working for me – Steering Committee*

> *We have to work it out ourselves how to manage our body. Control yourself. At the end, choice will become reality. So we are getting there. We have to build a bridge. So we have to plan – Steering Committee.*

This greater sense of control is associated with new knowledge and understandings of foods (particularly Western foods) and what they contain. This provides not only a means to make decisions about what to eat and how to act, but also a pathway to be able to access new knowledge about various things, not only health and well-being. This in particular helps with managing many of the issues that can come with community life, and at the intersection of Yolŋu and mainstream living practices.

> *The knowledge about the food just seems to change how you think about everything. That you have power, that you can find a way. Having that power, that control makes you feel good on the inside. Strong. The authority on the inside that you can do something – Dianne Biritjalawuy, SC Member*

> *It has given me more control, responsibility and purpose. Just living a normal life, not thinking about what to do for yourself. Not thinking like I was before. Now I am thinking I've got to do something. There is a way. How do I get there. I have to look for it. Get story. Other patients not thinking. Now every month we get blood test to see where we are now. Other patients don't know how to look for it. They don't know that. Now accessing that information and knowledge. I can look for things [that are good] for my body – Dianne Biritjalawuy, SC Member*

> *You become more stable. Like if anything comes at you, problem or anything, you know that you are strong, already. You have control and can do things, things that are right. But in town situation if people get food problem, financial problem, other problem, I always share [my story] with them. How I know how to go around things now – Dianne Biritjalawuy, SC Member*

Hope for Health staff cooking food at Galawarra

Riyala Retreat

Interviews were conducted with participants at the Hope for Health on Day 1 and Day 12 of their retreat experience. Interview questions were developed by Joanne Garŋgulkpuy in collaboration with Michaela Spencer.

Responses are clustered in relation to the 'Stories of Health' detailed in the previous section. Comparisons between early responses and responses near the end of the retreat help to trace changes in the perspectives, and health, of participants. Comparisons across the different stories of health help to reveal if, or how, these stories are being nurtured and maintained.

Riyala Retreat – Day 1

STORY 1: "Feeling Different" – Biomedical Story of Personal Health

At the beginning of the retreat, participants had some interest and awareness of a biomedical story of individual health, and a 'felt' sense of health and wellbeing. Many participants described themselves as feeling sick and unwell, and this was a reason to come to the retreat and to be interested in changing their habits.

> *"Was feeling too sick"*
> *"Sugar, diabetics go away"*
> *"High blood pressure"*
> *"Feeling weak, tired"*
> *"I had a heart attack and went to hospital. They put a camera inside to see my heart and little bit blockage. From that I was thinking to change my diet and also my wife has encouraged me to come here."*

For some there was a clear focus on issues of weight and weight loss, as well as how feeling heavy affected other everyday activities.

> *"Weight, thinking about that"*
> *"Feeling fat, tiredness, heavy"*
> *"Hoping for to lose weight, already gave up smoke for two weeks"*

There were also some participants who identified the types of food they were currently eating, and an interest in altering these habits and food types.

> *"Been eating flour, bread, syrup, corned beef, and orange juice"*
> *"Been eating takeaway, me and my wife"*
> *"I was feeling that the food was starting to kill me - junk food, sugar"*

STORY 2: "Sharing Health" – Story of Creating a Healthy Community

At this early stage, an interest in community integration was articulated a little more strongly by participants than the biomedical story. This was described as at the core of many people's interest in

health and new eating habits. An interest in becoming healthy so as to benefit the next generation was articulated by some retreat participants.

"Help the kids for the next generation, change Galiwin'ku"
"Do this for our children. Do this for own health and also our kids."
"Come here because children are on the long grass and want to help them out"

Connections between the activities of the retreat and other family and clan groups remained strong and were articualted by some participants.

"Different families live differently from different tribes. Here there are not many from our family group"
"Doing it for family on mother side, father side. Also for myself."
"Will help Galiwin'ku children, Mäpuru outstation, Ramingining, homeland"

There was a strong sense that the stories and efforts of previous Hope for Health participants had had an affect on the current attendees, and that word of mouth was an important way for news of the retreats to spread. This included work that Hope for Health staff were doing in the community.

"I was interested to come because other people told me the story"
"I came here to learn how to cook properly for myself and for my kids and for the family to show the good pathway"
"Was involved before I ever had interest because of my cousin sister who was in this retreat (she's from Gumatj tribe)"
"I came because the [Hope for Health] staff in the community were giving me good drinks. Lime, ginger, honey – make one for each household is what we should do. Top Camp, Bottom Camp, for children – instead of giving them drink all the time. Made them change from soft drinks."

STORY 3: "Yolŋu Food Story" – Story of Traditional Foods, Body and Place

Many participants talked about continuing to eat traditional foods (alongside sugary foods form the shop and takeaway) and going on regular hunting trips.

"When I'm at the outstation we eat fish, kangaroo. Go hunting every time"
"I'm often going hunting – fishing, spears"
"Families go hunting. But I go every morning to collect shells, maypal (shellfish), because I live near the sea"
"When children are sore in their mouth we make bush medicine"

There was also a sense that the bi-cultural element of people's health journeys was very significant, both because there is a tension between different foods that people currently eat, and because there is value in accessing different knowledges around health and health practices.

"Felt two foods fighting each other and coming together on my insides"
"We give our knowledge, and you give me yours"

STORY 4: "Retreat Story" – Story of the Retreat and its Effects

Participants' interest in the retreat was often linked to an interest in accessing new knowledge and experiences. As well as a sense that there is a need for new habits, and significant change. The retreat offered a way that people could leave the normal routines of their life, and have a break from these at the same time as altering their eating habits.

> *"Willingly went here, I was interested in the story"*
> *"Came here because family are here"*
> *"Good health, learn more about this program. What it is about, I have already learnt a lot about it from my family"*
> *"Expecting to have fresh one foods, vegetables, no sugar, water, walk, exercise"*
> *"Don't just sit and have the same going around and around. Get change! Hoping to improve myself and realise my goal. If I want to see that real change I'll never go back to that old stuff. I need to continue the new one. New life."*
> *"Was a time I was involved with some people from retreat – they were getting us over the bridge to the other side"*

STORY 5: "Staying Healthy" – Story of Self-Discipline and Control

On Day 1, the story of self-disipline and control was partially present, but not strongly articulated by many people. Participants knew that there were likely to be challenges on the road ahead, and some spoke of needing to persist but being unsure if change would happen.

> *"What is killing us? We need to change. No soft drink, lollies, grog, coke. Want to eat manymak (good) food"*
> *"Keep trying, keep going on for the future"*
> *"Stay healthy and strong. Each of my family. Encourage my family and friends."*
> *"I might be changed. But it's a question mark. Hard road"*
> *"Raypirri (discipline) – we need to help ourselves"*
> *"Why can't we control ourselves? Is it the spirit of sweet? Addicted?"*

Hope for Health participants gathering for dinner at the April Riyala Retreat

Riyala Retreat – Day 12

STORY 1: "Feeling Different" – Biomedical Story of Personal Health

By the end of the retreat, there was a marked change in the comments and stories being offered by participants. Many spoke much more openly and enthusiastically about a biomedical story of health, and how they were feeling in their bodies.

"Feel absolutely light"
"Everything feel good as I was going through the process of food, all medications, feeling good"
"Feeling light, not heavy one. Comfortable"
"Feeling good, good food, good exercise"
"More light, no more heavy one"
"Outside, inside feeling better"
"Fresh, light, happy, freshness in our body"
"Changes in our body"
"I am feeling that there is no sickness in me again. No-one else can feel inside of me. I have no sickness inside, I'm the only one that can feel it."

Much of this was attributed to changes in diet, including eating more vegetables, and regular exercise.

"Just saw food, "better eat what is there!" and didn't know it has a diseases"
"I'm finding the food good. It has made me light."
"Maintaining vegetables – vegetables a lot, not much meat was found (in our meals)"
"Sugar was coming up, up, up when I came here it went down"
"Feeling good, good food, going walking"
"Walking, working, staying together"
"Good vegetables, lots of water"
"All the muscles were in spasm, muscles are softer now"
"Helped people to be active, eat food"
"All really good. Vegetables really good, exercise"
"Learning what food was right, drink no sugars, only water, right food"
"Food good. Lots of vegetables, little bit meat, soup (mixed vegetables)"
"Walking every day, up and down with the group"
"Everything good – treatment exercise. Massage – was the first time I had that"

Participants described themselves as monitoring these changes through how they felt, but also through measurements of blood sugar, weight and reduced levels of pain and sickness.

"Sugar went down"
"Changes in blood pressure, sugar, medication"
"Coming off sugar good"
"Blood test gone down, getting normal, blood sugar normal"
"All the pressure, sickness went down"

"Lots of exercise, lost weight"
"Changed, not feeling the pain I had. Its all finished now."
"Back at home feeling sick all the time, here has changed"
"Before cigarettes and asthma puffer. Now no cigarettes, go everywhere in the camp"
"The food and pills worked together, team work"
"There is two things – naturopath and medication. Medication is from doctor in community.
"Naturopath gave us a supplement, we are eating those. Supplement is a food medicine, and in medication is chemical. That's where we going to compare and will say to the doctor"

STORY 2: "Sharing Health" – Story of Creating a Healthy Community

There was also a considerable increase in discussion around creating a healthy community by the end of the retreat. Participants were inspired to maintain what they had learned, and to help support and change Galiwin'ku through these efforts.

"When I go back I'm going to sit with families and talk about vegetables"
"Right food, need to show the families. Need to demonstrate it to the family"

"What was good was going and sitting with families, telling stories, getting ideas for them, getting ideas about how Hope for Health can run and how they can eat food and want to expand the program"

"Opportunity for me to learn more special thing for future generation of my people"

"In my house and families give them good food and ask them and help them so they can get good food from the shop. Help with good shopping, good walking

"Shopping together, sharing jobs together"

The Yolŋu Hope for Heath staff were seen as crucial to these efforts. It is their work which helps to extend the program to new people. It also offers assistance which goes beyond just discussion of food, but is concerned with all aspects of community life, and ways to work and talk together to find new solutions and ways of recovering some of what has been lost in Yolŋu life. It is not just the process of eating, but also making food together that is important.

"Good ŋatha (vegetables), cooking and from those 5 who came in from Galiwin'ku as cookers. They will keep cooking"

"Action when we come back – encourage people to care and see how we can cook together. Children and adults. They come every afternoon, sit and cook. They are making juice and cooking food. Sometimes we sit and share together. Telling stories, what we have been going through. Where we see. Making a plan. Trying to encourage other people too."

"Drawing people, the real Yolŋu. Not just for them to eat food, but everything we have lost. Help with their houses to make things work. Not just the food, its all the other things – house cleaning, inside, outside. Doing this I work with family, everyone"

"Start doing new things we've learnt here, share it with others"

There was also a strong sense of the need to maintain and stabilise this work in Galiwin'ku, so that there is a place in (not away from) the community where people can come, and these activities can continue. Preparation of Yolŋu foods occurs in place, and transitions to preparation of Westen foods also needs consideration of *where* foods are prepared.

> *"Is a good program for Yolŋu for Arnhem Land, all over Arnhem Land."*
>
> *"Hope for Health should be a permanent program in the community. Find a place that is good for people to come and take part"*
>
> *"Effective program for Yolŋu to visit where they come from"*
>
> *"If we find it hard we have to encourage ourselves. Build up strength together, encourage one another, look to the track where we are going. It will be back in our community. If we want to plan ourselves something for a year, see how we have to go through"*
>
> *"This is a turning point for our children. Have to say 'You stop' because we have been going through this and want you to turn and have long ago what people used to have in that system eating well together. Still have to train them, teach them, train them and give our knowledge back to them. There is not many old people left"*

STORY 3: "Yolŋu Food Story" – Story of Traditional Foods, Body and Place

By the end of the retreat, alongside increased discussion around biomedical and community development stories of health, there was also more discusison of differences between Western foods and Yolŋu traditional foods and preparation pracices. This comparison seemed helpful for some, as they began to reflect on ways to maintain Yolŋu traditions while also managing Western dietary practices (good and bad) in the community.

> *"This morning feeling sad about the story we heard. About how we (Yolŋu) went wrong – what was tempting us in the first place, and ate a lot of food that belong to someone else"*
>
> *"Even though my people went the wrong way, we know the right place is here with us now and have to revisit that place and renew what is being lost"*
>
> *"We have many things so we have to revisit, find our way back, through gurruṯu (kinship). Look at kids and go through gurruṯu (kinship), that's how to get things right for them"*
>
> *"For Yolŋu people, where we are going, what we are eating – make it for children. In our law is a song, a food, a ceremony, we have been there"*
>
> *"We've been cooking yams, we ate cycad nut last week – put in running water, put it under the bark and wrap it up and put it under each oven. Next day comes out we unwrap it and broke it into parts"*

There were also some suggestions made as to how an emphasis on shared learning through and between Yolŋu and Western knowledges of foods could be sustained within Hope for Health, and future retreats. Potentially also considering places, and practices of relaxation – like the breeze on your face – which are important for Yolŋu.

"Need session or course on each food – how to know about it, organise and cook for everyone. Story for each food e.g. for yams there is a story how to eat them, story for cycads, how to prepare for eating. Every food on the plate in this dining room should have a story"

"Was difficult to go out hunting at the retreat. We like the beach feeling the west wind. Always we have relaxation at the beach"

"What was hard was going to excursion only in one places, good to visit other areas for relaxation"

STORY 4: "Retreat Story" – Story of the Retreat and its Effects

Many participants commented on the peaceful surrounds and atmosphere that were offered by the retreat, and how this allowed them to have a break from their everyday stresses and routines.

"Everything change around me, a peaceful atmosphere"
"I got encouragement from everyone"
"Coming here was good to have a peace and quiet time, no more humbug, yapping"
"It was stressful at home, and relaxing here"
"You don't find this back at home, different to community"
"Felt good here where not much people family. Have provided sheets, bed, shampoo all sorts of things. Listening and learning new ways of eating and cooking"
"Participating – doing exercise, helping each other, doing painting, weaving, lots of activities"

There was value placed on the learning opportunities that the retreat provided, both in terms of developing a better understanding of (Western) foods, and ways to prepare these foods at home.

"Learnt about food, vegetables, food with vegetables has helped the body"
"Hear about the right food, water, tea (no sugar). No damper"
"New people here are learning, listening"
"Showing how to cook – new healthy food, drinks with vitamins, tea"

Understandably, for some the journey had presented some sense of difficulty and hardship, with several participants noting how the change of diet and location had been challenging.

"Juice – first day hard, second hard, last third day was good"
"All the food made me hungry. Felt very hungry all the time"
"Wanted to be eating steak, but vegetables ok"
"No shopping, no takeaway food, missing tea, no powdered milk"
"Hardest part was not going shopping"
"After the beginning fasting we should have been on full food. Last time we had full food after the fast"

Note: These discussions were held before the shopping trip in Darwin at the end of the retreat.

STORY 5: "Staying Healthy" – Story of Self-Discipline and Control

By the end of the retreat there was not a significant growth or alteration in the participants comments around self-discipline and control. Given the strong emphasis on this element of health expressed by Steering Committee members and staff, this seems to suggest that this story takes longer to develop, and may become significant as participants return to Galiwin'ku and seek to maintain the practices they have learned at the retreat.

> *"I was battling inside, mind was saying 'don't go'. Took me 2-3 days to fight over this thinking but my own will power said 'go' [to the retreat]. The green light"*
>
> *"Having a supplement at the moment and that's how we have to be control ourselves by eating when we go back to our communities. That's where we should be controlling ourselves"*
>
> *"When we go back because there will be so many temptations there. We can be careful of what we eat, our taste of what we are eating"*

Joanne Garŋgulkpuy leads discussions with Hope for Health participants at the April Riyala Retreat

RIYALA RETREAT – 3 month follow-up

STORY 1: "Feeling Different" – Biomedical Story of Personal Health

Three months after the end of the retreat, some of the participants described its effects in terms of good reports, or the absence of bad reports, from the doctor. There was pride in gaining a good bill of health from the clinic, and in having kicked unhealthy habits. Some had been experimenting with different kinds of food supplements, as provided at the retreat, and finding which worked for them. A few talked of noticing cause and effect relationships between returning to old eating habits, and the noticeable effect this had on weight and health.

> *"I want to drink water, not soft drink"*
> *"Still taking supplements. Some work and others not"*
> *"I have no story to tell about the doctor, because I don't have any medication. That diabetes all gone. Sugar level excellent, blood pressure, heart, everything is fine. I've gone back to the clinic."*
> *"He said you have to stick to that food"*
> *"I was heavy smoker and I went to retreat and it changed. When I came back, I just stopped – April, May, June, July"*
> *"Been to clinic, everything good"*
> *"In June I went down, and started to eat bad food. My weight went up afterwards"*
> *"Came back and felt good, then energy goes down. Went back to eating old foods – rice, bread meat, vegetable. Cooking."*

STORY 2: "Sharing Health" – Story of Creating a Healthy Community

There continued to be an aspiration amongst retreat members to spread the opportunity for health and healthy eating amongst the younger generation, and some described ways they were doing this for their family.

> *"Our aim is we need to share and put into action to our children and young generation. We have to carry out and stand and our children should be getting these supports and learning processes."*
> *"To do the work they are both doing to before achievement and benefit of this community"*
> *"Because they and we are looking to benefit of this community. And how to overcome of that, even the government will see because of this work we are doing"*
> *"I tried once to create menu, to have plan, but it's hard"*
> *"I've been cooking small food (controlled portions) with my family"*

A common story also told was that it was difficult to maintain good eating practices yourself, or amongst your family, when income flows are not stable. While it is possible to purchase and cook healthy foods on a week when pay arrives, it is harder to do this in off weeks, where you are relying on family (and what they choose to eat) for food.

> *"A lot of people live in one house and share with all family, we share the food with other family"*
> *"Cooking for yourself is easy. But hard part is coming back to community is hard. Some people cook, and some people don't. Dole just lasts for a few days. Not enough for good food."*

"People at ALPA (local store) know how to put price up or down"
"We have a lot of population growing up in Centrelink, the money is in and out [which effects food security]"
"Sometimes problem money, no rrupiya (money) so it's hard to buy food. Sometimes I ask family and have to eat what they are eating. No money, ask family. They give sweet stuff."
"Family were interested to listen to the [Hope for Health] story, but when I told them they didn't hear it"

STORY 3: "Yolŋu Food Story" – Story of Traditional Foods, Body and Place

Participants spoke positively about elements of the retreat that included cooking and eating traditional Yolŋu foods. They looked back to a time when Yolŋu were strong, healthy and active people, having some pride in this past as well as sadness for how it is difficult to achieve these days.

"People in those days were hardworking, always walking. Walking mangrove, looking [for shellfish]"
"Lots of ganguri (yams), dingu (cycad nuts) at Riyala. We put in coals to cook"
"Yolŋu used to always be sharing not just teabag, flour. These things cost money and stop the sharing"

However, there was also a tension between similar fond memories of Yolŋu have for mission foods (damper, tea and sugar), and a growing awareness that these foods are unhealthy and should be avoided.

"Born in that lifestyle of eating damper. Was what we knew"
"We were cooking damper in coals, then Broc came along. What should we do? (because knew should not be eating it). Leave in there hidden till it cooks hard?"

Story 4: "Retreat Story" – Story of the Retreat and its Effects

Understandably, after the retreat, and with some time to reflect, participants had a lot to say about the next steps for the program. Much of this discussion was focussed on how to maintain health whilst in Galiwin'ku. Priorities centred on: having a Hope for Health space (larger than the premises already available); recognising the value of the program as partly in the coming together of different knowledge traditions; and maintaining Hope for Health staff able to support cooking classes and exercise activities.

"First time went to Riyala manymak (good). Second time, very very manymak (good). Third time, I'm very shrinking now!"
"We really need a space here in Galiwin'ku. A place that has room for kitchen, food, activities"
"Not just squashed and sitting on veranda. They should put library somewhere else. Build a really good, library, then we can have that old library space"
"Where should this meet together? Team working, collaboration. This is what we have to see"
"We are sharing the knowledge. Hope for Health are seeing and sharing knowledge, and clinical health also has to share. We can see those things have to be done to make it a success"
"Really good having someone here"
"Morning walks have been good, follow up on the ground here in Galiwin'ku"

"Always demonstrating how to cook. Broc always doing that. Printing out recipe and give it to everyone. Helps so we can read how to cook, put spice in. Use coconut milk, oil, cream. Salad dressing – hand made"
"We need that Hope for Health staff to keep going. Continue going on. Every day meeting, talking, encourage one another. Managing, supporting, getting strong, strong, strong. Cooking at home. Keeping going"

Story 5: "Staying Healthy" – Story of Self-Discipline and Control

Having been faced with the challenge of coming back into the community and continuing new cooking and eating habits after the retreat, discussion of temptation and self-control featured more strongly in participants' discussions than it had previously. Temptation was recognised as lying in the food itself, as produced through pressure from children and others. There were positives and negatives which accompanied new knowledge of foods, and the concept of choice. On the one hand, certain choices are now possible. On the other, this can bring up feelings of hesitancy and frustration around how to navigate this new terrain.

"When go by myself I know what to get, when I go with the grandchildren it is hard"
"Food is asking you to buy it"
"Only the good vegetable is when we get paid – good food, vegetable, meat on payday time.
"Sometimes they [family] share, sometimes don't want to do big shopping"
"Before was only mother and father in house with children. Now have to control more for self"
"Before family used to control each other"
"Now in shop choosing – buy good food or bad food. Drink or water"
"Now lots of temptation around us, house, family"
"Yesterday, this morning thinking to go back walking"
"Balance is important and hard. Still eating some pie, drink, lollies"

3-month follow up discussions with Hope for Health staff and participants at Mission Beach

Evaluation Tool

This tool draws on the learnings and experiences of this piece of research and is designed to be functional within future retreat settings. The two sets of questions are focused towards eliciting responses from participants before and after the retreat.

The tool for recording and analysis offers a method for interpreting responses so as to produce a growing evidence base that can demonstrate the outcomes of the retreats, and support further iterative development of the Hope for Health program.

Evaluation questions:

These questions have been derived by sets of questions proposed by Garŋgulkpuy and used in the retreat evaluations at Riyala. At this retreat, we sat down with small family groups and asked people to respond to the questions in an interview format. Garŋgulkpuy has suggested that another possibility would be for a larger group of people to sit together, perhaps around a fire, and to discuss the questions together. There would also be other possible formats.

Before

1. Where have you come from? What types of experience have you been having with eating and activities (like hunting, walking)?
2. Why did you get involved with Hope for Health?
3. Who is this for? (e.g. for family, yourself?)
4. What are you expecting?
5. When you finish at the retreat, how will you keep going?

After

1. How are you feeling right now?
2. How was the food in HfH? How were the activities, the treatments?
3. What has been good? What has been hard?
4. Has anything changed for you by coming here?
5. What are some of the things you have learnt from HfH?
6. How might we keep this work going? (though things you will do or change at home, and through additions or changes to future retreats?)

Recording and Analysis

The responses to the previous two sets of questions, can then be clustered according to the various 'stories of health' which have appeared as significant in the accounts of Steering Committee members and staff.

"Feeling Different" Biomedical Story of Personal Health	• … • … • …
"Sharing Health" Story of Creating a Healthy Community	• … • … • …
"Yolŋu Food" Story of Traditional Foods, Body and Place	• … • … • …
"Retreat Story" Story of the Retreat and its Effects	• … • … • …
"Staying Healthy" Story of Self-Discipline and Control	• … • … • …

Responses that seem relevant to each of these particular stories can be clustered under these headings. Using a table like the one listed, or through other means (e.g. graphically on a picture or chart).

These clustered responses work in two ways:

- They evidence long-term engagement with health as a complex and multiple issue, and record perceptions of different aspects which need all be maintained, and carefully interrelated, in the service of responsible change in-place
- They enable Hope for Health organisers to track imbalances across these multiple aspects, identifying areas where extra support may be needed, where routines or practices could be modified or abandoned, or an over-emphasis can be identified and remediated.

Hope for Health staff and participants at the April Riyala Retreat.

Part 2:

Biomedical Research

Biomedical Research

Background

The University of Melbourne (Dr Sarah Hanieh (MBBS, PhD, Research Fellow) and Professor Beverley-Ann Biggs (MBBS, PhD, Head of Immigrant and International Health at the Peter Doherty Institute for Immunity and Infection, University of Melbourne) performed an evaluation of the Hope for Health program in 2019. The main objectives of this aspect of the evaluation were to:

i) Document health indicators of participants at baseline, during retreat and three months post retreat

ii) Determine the impact of the Hope for Health program on health outcomes at 3 months post retreat, compared to health outcomes at baseline (pre-retreat).

Methodology

Study Design

This was a pre-post evaluation of participants taking part in the April Hope for Health retreat. Primary outcomes of interest were i) dietary patterns; ii) participant anthropometric outcomes (weight, body mass index, waist circumference; and iii) clinical biomarkers (cholesterol levels, HbA1C, fasting blood glucose).

Study population and site

The baseline pre-retreat evaluation was conducted between March 18th and March 22nd on Galiwin'ku, Elcho Island. All participants enrolled to take part in the April Hope for Health retreat and present in Galiwin'ku were eligible to take part in the baseline pre-retreat evaluation. The Hope for Health retreat took place in Riyala, Darwin, Northern Territory between April 1st and April 14th, 2019. The post-retreat evaluation took place between July 15th and July 19th on Galiwin'ku, Elcho Island. All participants who took part in the April Hope for Health retreat and were present in Galiwin'ku were eligible to take part in the post-retreat evaluation. Participants who were not present in Galiwin'ku during the post retreat evaluation were followed up at a later stage in Galiwin'ku by Mr Broc Martin (Health Coach Mentor from Hope for Health).

Ethical Approval

The study protocol was approved as a Quality Assurance project by the Melbourne Health Human Research Ethics Committee (QA2019022). Verbal informed consent was obtained from all participants prior to participation in the evaluation.

Data collection

The field team consisted of Dr Sarah Hanieh and Professor Beverley-Ann Biggs from the Department of Medicine at the Peter Doherty Institute for Immunity and Infection, University of Melbourne. Participants who had signed up for the Hope for Health retreat and therefore eligible to take part in the evaluation were identified by Mr Broc Martin. Data was collected via the use of a mobile tablet device using the Research Electronic Data Capture System-RedCap.

Questionnaire. Socio-demographic, nutritional, environmental information was collected using a structured questionnaire via RedCap at baseline and three months post-retreat.

Clinical and Anthropometric measurements Weight was measured using digital weighing scales with precision to the nearest 10 g (Seca 803) at baseline, day one and day twelve of retreat, and three months post retreat; height was measured using a flexible measuring tape at baseline; and waist circumference was measured using a flexible tape around the waist at the mid-point between the lowest ribs and the hip bones at baseline, day one and day twelve of retreat, and three months post retreat. Body mass index (BMI) was calculated as weight in kilograms divided by height in square meters. Blood pressure was measured using an automated sphygmomanometer at baseline, day one and day twelve of retreat, and three months post retreat.

Clinical Biomarkers: Fasting plasma glucose was measured using a blood glucose meter on day 2-14 of retreat, and three months post-retreat; and venous blood was measured for glycolated haemoglobin (HBA1c), and cholesterol and lipid profile (Total Tri-glycerides, HDL-C, LDL-C,) at baseline and three months post-retreat. Venous blood was collected by staff at Miwatj Health and analysed at Western Pathology as part of routine care.

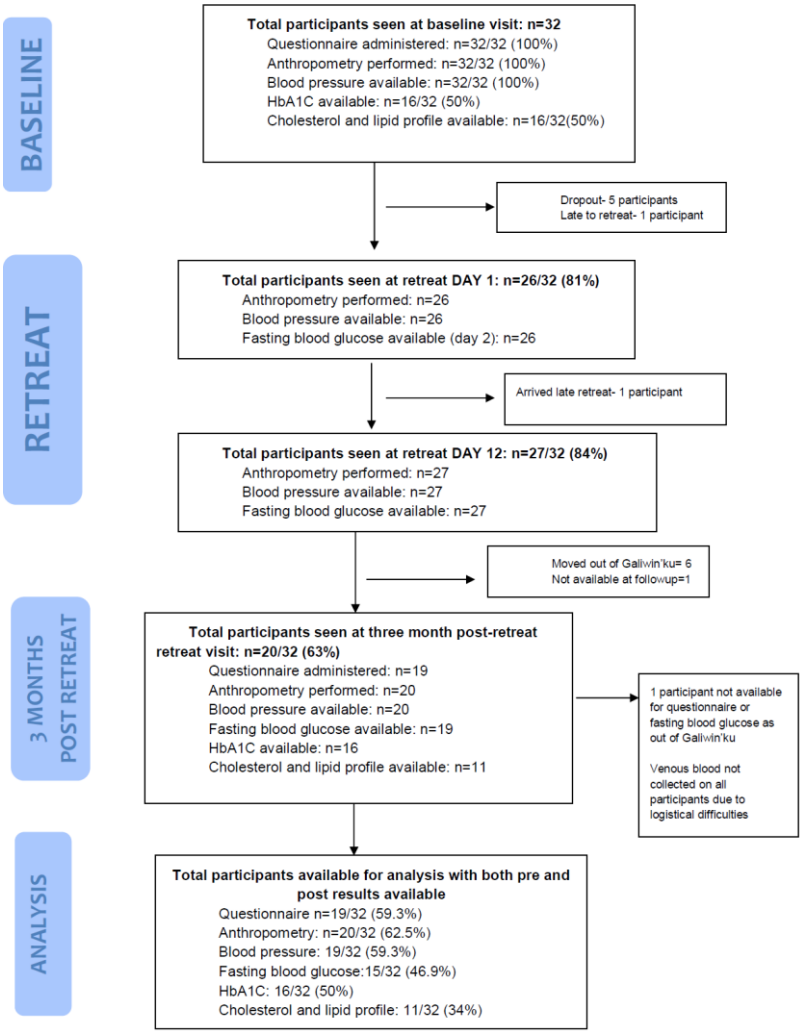
Statistical analysis

Data was analyzed using StataIC, version 14 (StataCorp, College Station, TX, USA). Categorical data are presented as percentages with frequency, and continuous data are presented as mean and standard deviation (SD). Only participants with both baseline and three months post retreat tests were included in the final analysis for statistical comparison. The difference between pre- and post-test results was tested for statistical significance using McNemars test for paired categorical data and the t-test for continuous data.

Results

A flow diagram is presented in Figure 1. In total, 32 participants were seen at baseline, 27 participants took part in the retreat, and 20 participants were seen at the 3-month post retreat follow up. Participants with both pre and post results available are presented in Figure 1.

Figure 1. Flow diagram



Sociodemographics: The average age of participants was 46.1 years and more than 80% were female. The majority of participants (43.8%) were educated to year 10 level. More than 40% of participants were smokers and the average number of residents per household was 8. Baseline socio-demographic characteristics are presented in Table 1.

Table 1. Baseline characteristics of participants (n=32)

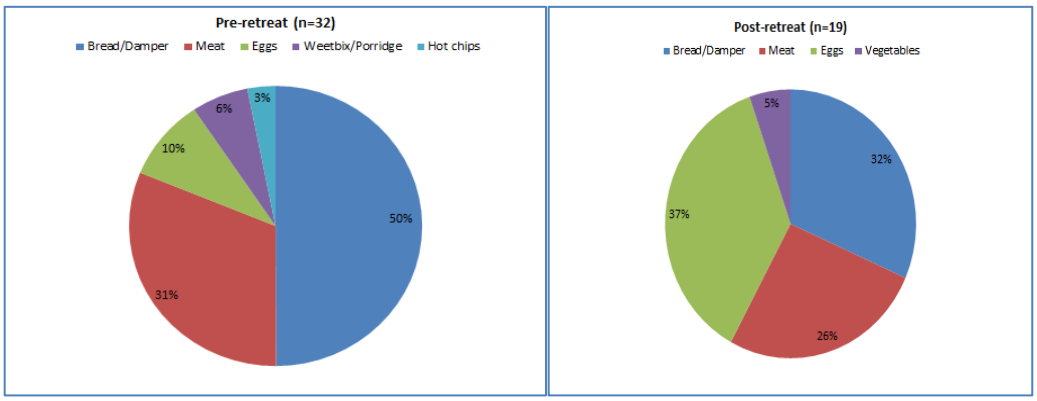
Characteristic	Mean [SD], median {min-max} or number (%)
Socio-demographic	
Mean age (years)	46.1 [12.7]
<20 y	3 (9.4)
21-45 y	11 (34.4)
>45 y	18 (56.3)
Sex	
Male	6 (18.8)
Female	26 (81.3)
Education	
Year 8-10	14 (43.8)
Year 11	5 (15.6)
Year 12	13 (40.6)
Post-secondary qualification	14 (43.8)
In paid employment	17 (53.1)
Currently receiving government benefits	23 (71.9)
Smoker	13 (40.6)
Number of people living in house	8 {4-20}
Medical history of diabetes	9 (28.1)
Medical history of hypertension	11 (34.4)

The following section reports total participants who took part in the retreat. This includes those who have previously attended a retreat (largely local staff and committee members) as the great majority being first time participants. A sub-analysis of first-time participants only follows this section.

Analysis of All Participants

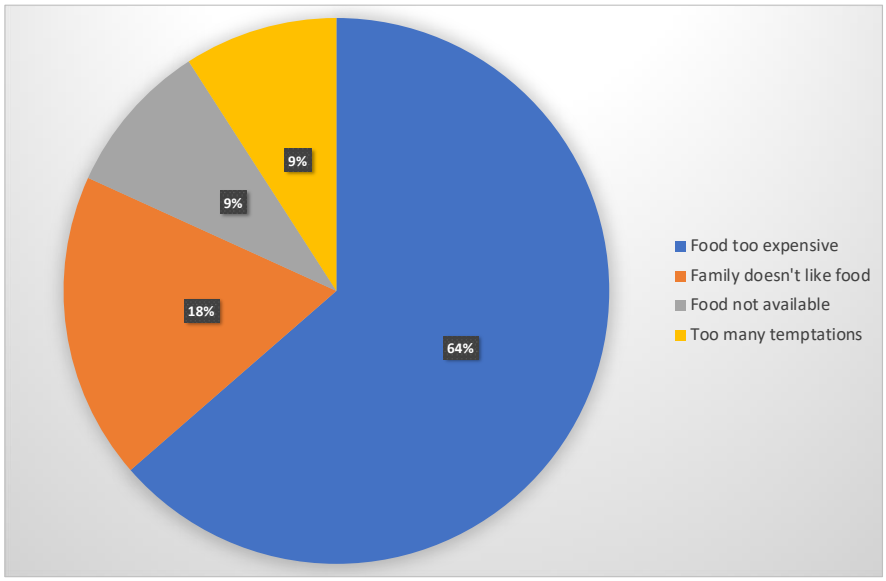
Dietary patterns: Food insecurity was common in this setting with 53% of participants reporting they had missed a meal or gone hungry in the last two weeks during the pretreat interview, and 64% reporting food insecurity during the post-retreat interview. Pre-retreat, the most commonly eaten foods reported by participants were bread/ damper (50%) and meat (31%). Post-retreat, bread/damper (32%) and meat (26%) were still commonly eaten by participants, however there was a significant increase in egg intake (37%). Differences in dietary patterns pre and post retreat are presented in Figure 2.

Figure 2. Most commonly eaten foods as reported by participants.



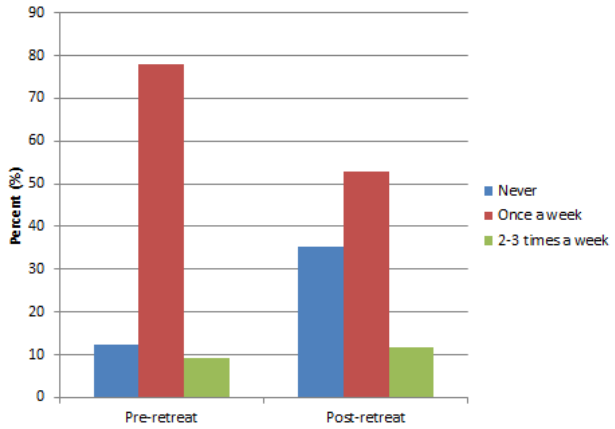
More than 60% of participants reported that the diet was difficult to stick to after leaving the retreat and returning home to Elcho Island, at the three months post retreat interview. Reasons are presented in Figure 3, with the majority of participants reporting food expense as the biggest barrier to maintaining the diet (64%).

Figure 3. Reasons for difficulties in sticking to diet, as reported by participants at three-month post-retreat follow up interview.



Patterns in traditional hunting pre and post retreat are presented in Figure 4. The majority of participants reported going hunting once a week, both pre and post retreat.

Figure 4. Frequency of traditional hunting as reported by participants.



Clinical measurements: Anthropometric measurements pre and post retreat are presented in Table 2.

Table 2. Anthropometric and clinical measurements of participants' pre and post retreat.

	Baseline (pre-retreat) Mean [SD] or number (%)	**Day 12 of retreat**	**Significance [1]**	**Three months post-retreat** Mean [SD] or number (%)	**Significance[2]**
Weight (kg)	78.7 [14.5]	76.2 [17.5]	**<0.001**	77.1 [14.9]	0.05
Waist circumference (cm)	103.8 [10.4]	99.7 [10.7]	**<0.001**	101.1 [11.7]	**0.03**
At risk for chronic disease (>94cm for men, >80 cm for women)	17 (94.4)	17 (94.4)	>0.5	17 (94.4)	>0.5
Body mass index (kg/m2)	28.5 [5.1]			27.9 [5.3]	0.05
Normal weight (18.5 to 24.9)	6 (30)			8 (40)	
Overweight (25.0 to 29.9)	7 (35)			5 (25)	
Obese (>30)	7 (35)			7 (35)	

Blood pressure (mmHg)	119/80	124/85		129/85	
Hypertension[3] (systolic BP>=140 and/or diastolic BP>=90)	7 (36.8)	6 (30)	>0.5	7 (35)	>0.5

[1] Difference between baseline and day 12 of retreat

[2] Difference between baseline and three months post retreat

[3] Eleven participants were documented as having hypertension. Ten participants were documented as being taken off their medications for hypertension at the commencement of the retreat, and two participants recommenced their anti-hypertensive medications during the retreat.

Weight: There was a significant weight loss amongst participants from baseline to Day 12 of retreat (p**<0.001**). There was a trend towards a decrease in participants mean weight at baseline compared to three months post retreat, however this did not reach statistical significance (p=0.053) (Figure 5). Mean weight over time is illustrated in Figure 6.

Figure 5 Mean weight (kg) at baseline and three months post retreat

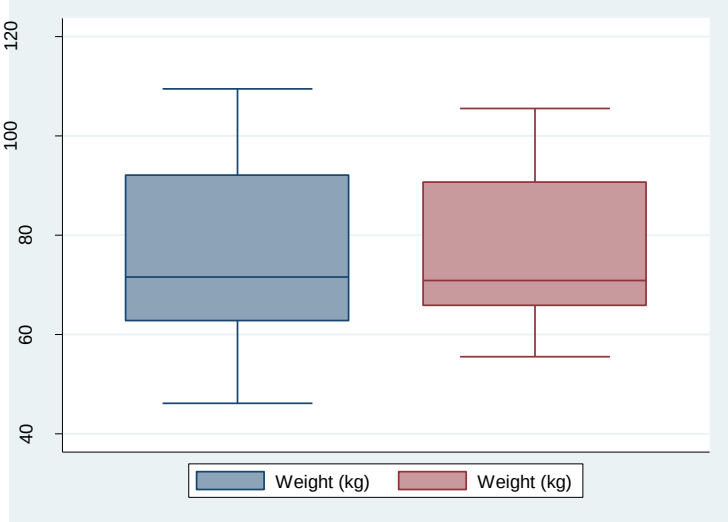
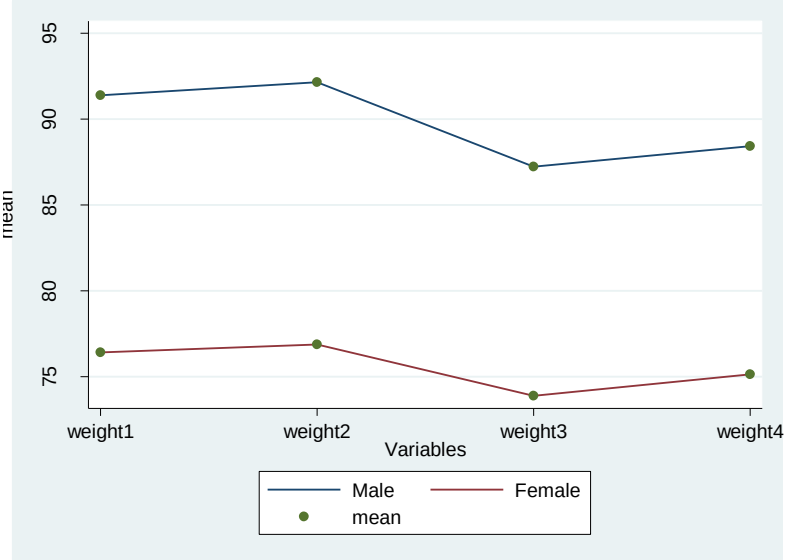


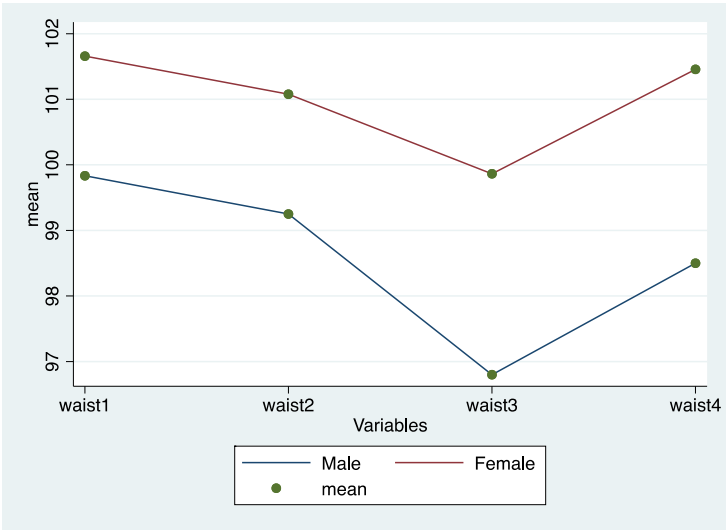
Figure 6. Mean weight (kg) of participants over time, by sex.



Weight 1= Baseline, Weight 2= Day 1 of retreat, Weight 3= Day 12 of retreat, Weight 4= Three months post retreat.

Waist circumference: There was a significant decrease in waist circumference amongst participants from baseline to day 12 of retreat (p**<0.001**), and this decrease was sustained until three months post retreat (**p=0.03**). However there was no change in the proportion of participants who were characterized as at 'high risk for chronic disease' at baseline, day 12 of retreat or three months post retreat (94.4%). Mean waist circumference over time is presented in Figure 7.

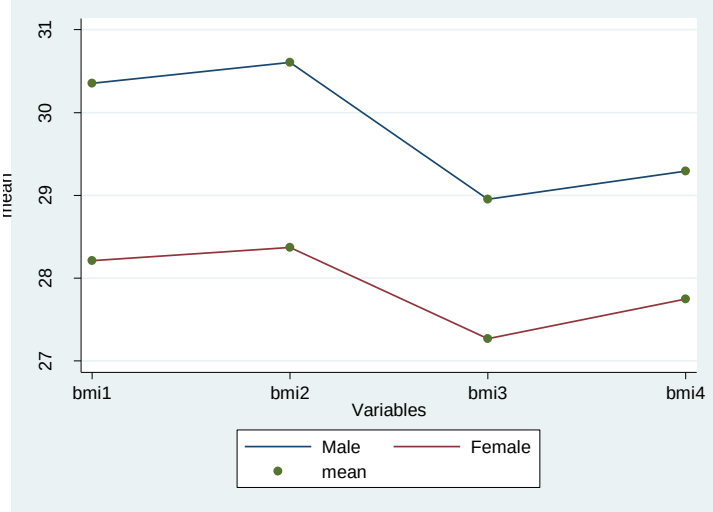
Figure 7. Waist circumference (cm) over time, by sex.



Waist 1= Baseline, Waist 2= Day 1 of retreat, Waist 3= Day 12 of retreat, Waist 4= Three months post retreat.

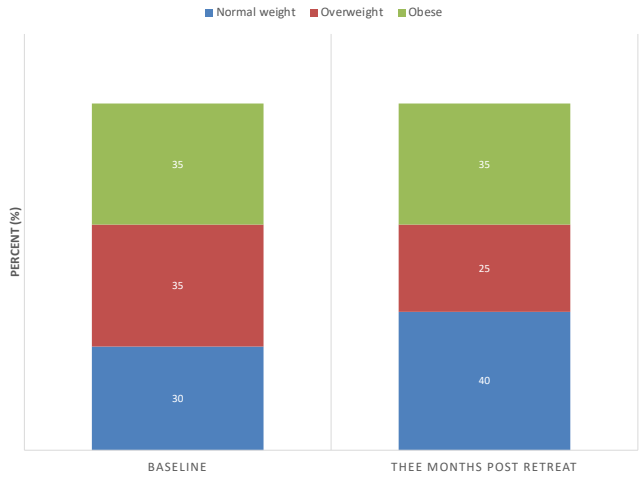
Body mass index: Mean body mass index over time is presented in Figure 8. There was a trend towards a significant decrease in body mass index from baseline (28.5 kg/m^2) to three months post retreat (27.9 kg/m^2) (mean difference =0.55, p=0.05). Body mass index categories are presented in Figure 9. There was no statistically significant difference in the proportion of participants overweight/obese at baseline (70%) and 3 months post retreat (60%) (p=0.16) (Figure 10).

Figure 9. Mean body mass index over time, by sex.



bmi1= Baseline, bmi2= Day 1 of retreat, bmi3= Day 12 of retreat, bmi4= Three months post retreat.

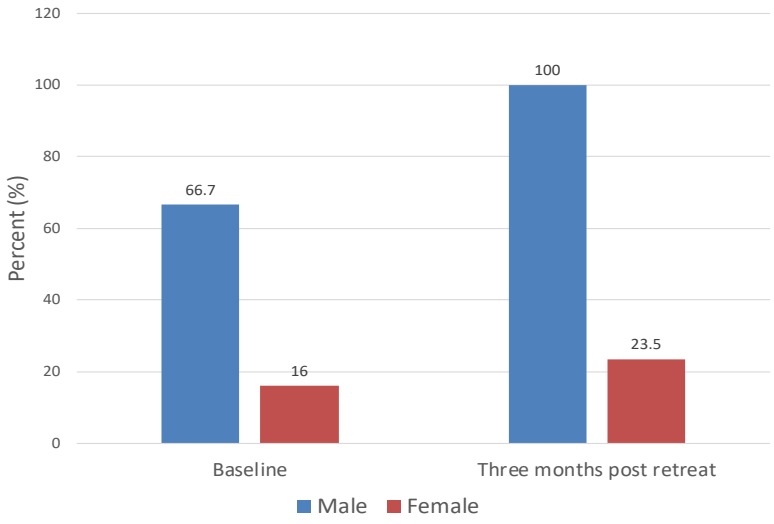
Figure 10. Body mass index categories at baseline and three months post retreat



Blood pressure: There was no significant difference in participant's mean systolic or diastolic blood pressure between baseline and day 12 of retreat (p>0.5) or baseline and three months post retreat (p>0.5). Prevalence of hypertension was 36.8% at baseline, 30% at day 12 of retreat, and 35% at 3 months post retreat. (Figure 11). There was no statistically significant change in the proportion of

participants with hypertension at baseline and 12 months retreat, or baseline and three months post retreat. Ten participants were documented as being their blood pressure medication ceased for hypertension at the commencement of the retreat, and two participants recommenced their anti-hypertensive medications during the retreat. There was no change in the significance of results when adjusting for participants who had blood pressure medication ceased.

Figure 11. Prevalence of hypertension in participants at baseline and three months post retreat.



Biomarkers: Blood results from participants are presented in table 3.

Table 3. Blood results from participants

	Baseline (pre-retreat) Mean [SD]/ median {25th to 75th IQR}/ or number (%)	**Day 10 retreat** Mean [SD] or number/ (%),median {25th to 75th IQR}/ or number (%)	**Significance[1]**	**Three months post retreat** Mean [SD] or number (%)	**Significance[2]**
Fasting blood glucose (mmol/L) [3]	5.5 {4.6 to 7.7}	5.5{4.8 to 6.5}	0.88	7.2 {5.2 to 11.5}	**0.02**
Elevated fasting blood glucose (>=7mmol/L)	8 (42.1)	5 (25)	0.15	11 (55)	0.18
HbA1C	7.8 [2.2]	N/A	N/A	7.5 [2.2]	0.13

Elevated HbA1C (>7)	7 (43.8)	N/A	N/A	6 (37.5)	0.56
Cholesterol (mmol/L)	4.1 [0.94]	N/A	N/A	4.61 [0.72]	0.06
Triglycerides (mmol/L)	1.75 [0.81]	N/A	N/A	1.68 [0.63]	0.76
HDL	0.95 [0.19]	N/A	N/A	1 [0.23]	0.19
LDL	2.4 [0.81]	N/A	N/A	2.84 [0.63]	0.07
Coronary Risk Ratio	4.5 [0.98]	N/A	N/A	4.72 [0.71]	0.36

[1] Difference between baseline and day 12 of retreat

[2] Difference between baseline and three months post retreat

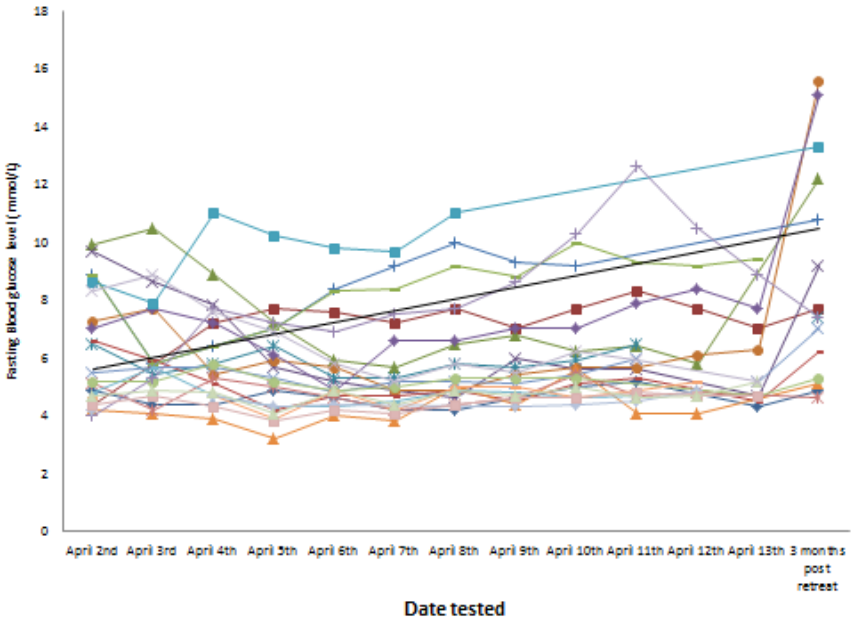
[3] Measured on Day 2 of retreat

Fasting blood glucose: From information available at the time of analysis, there were nine diabetics on retreat and all were taken off their medication during the retreat. Two participants recommenced their medications during the retreat. There was no significant difference in fasting blood glucose from the start of retreat to day 12 of retreat. Fasting blood glucose of individual participants over time is plotted in Figure 11, and mean fasting blood glucose of participants by sex is shown in Figure 12. There was no statistically significant change in the proportion of participants with elevated fasting blood glucose at the start of the retreat and three months post retreat.

HbA1C: There was no significant change in mean HbA1C from baseline (7.8) to three months post-retreat (7.5), (p=0.13). Prevalence of elevated HbA1C was 43.8% at baseline, and 37.5% at three months post retreat. There was no statistically significant change in the proportion of participants with elevated Hba1C at baseline and three months post retreat (p=0.56).

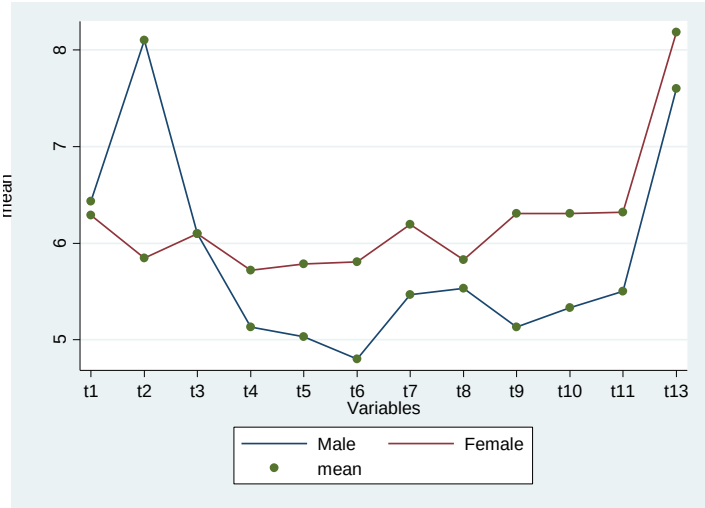
Cholesterol and lipids: There was no significant change in mean levels of cholesterol or lipids from baseline (pre-retreat) to three months post retreat (Table 3), or in the proportion of those with elevated cholesterol and lipids before and after attendance at the retreat.

Figure 11. Fasting blood glucose of individual participants over time



***The majority of participants stopped diabetes medication at the beginning of the retreat.**

Figure 12. Mean fasting blood glucose participants over time, by sex



T1= Day 2 of retreat, T2-T11=day 3 to day 11 of retreat, T13= three months post retreat.

Figure 13. Prevalence of high HbA1C at baseline and three months post-retreat.

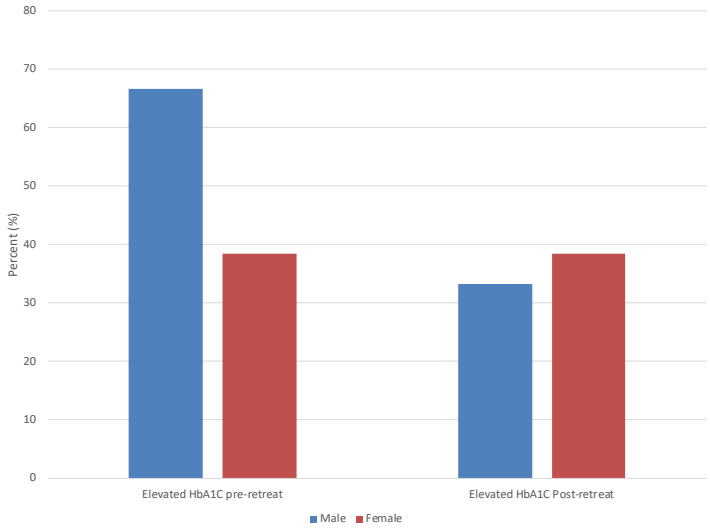
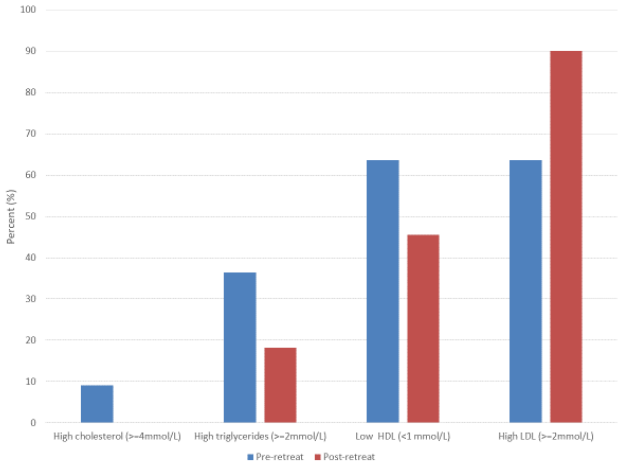


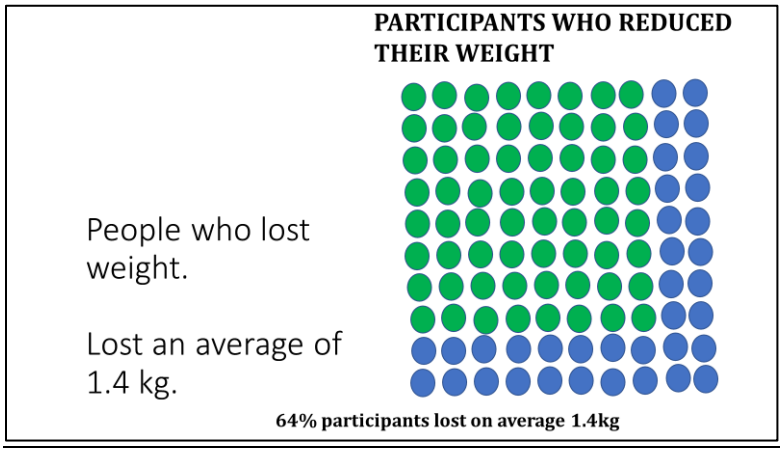
Figure 14. Prevalence of elevated cholesterol and lipids at baseline and three months post-retreat.



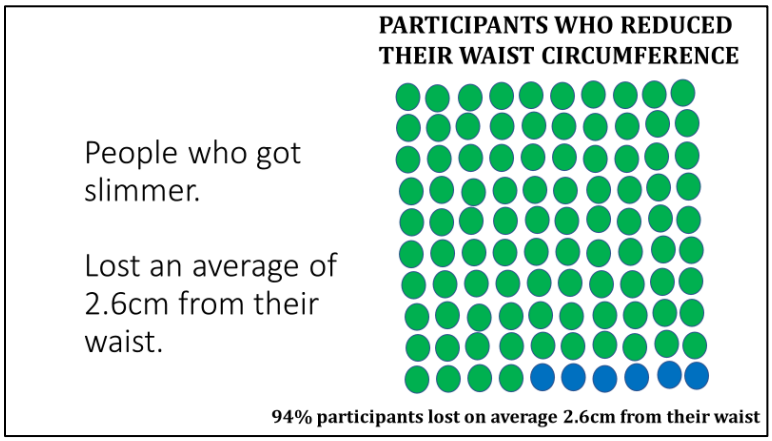
Sub-analysis of first time participants

A sub-analysis was also performed on first time participants. The following results show only participants who have not attended a retreat previously (n=11). The illustrations show all results together as a percentage (out of 100). These results are from check-ups held 3 months after the retreat. Due to low numbers formal statistical analysis was not performed.

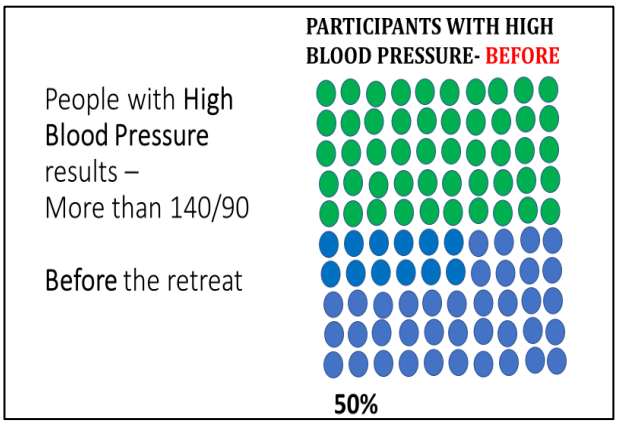
Weight

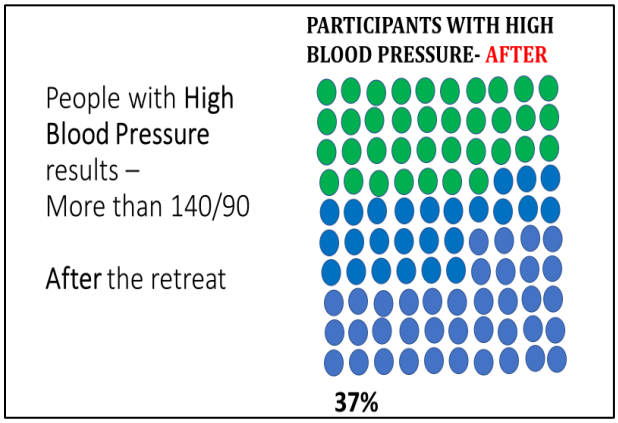


Waist circumference

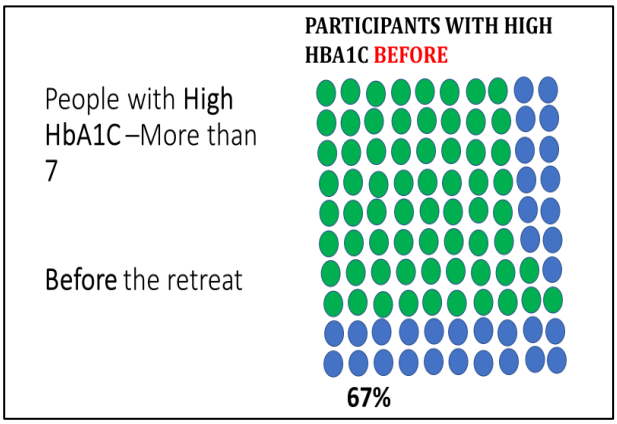


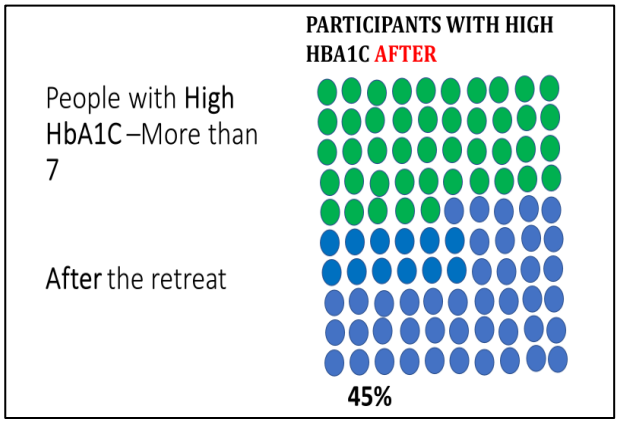
Hypertension



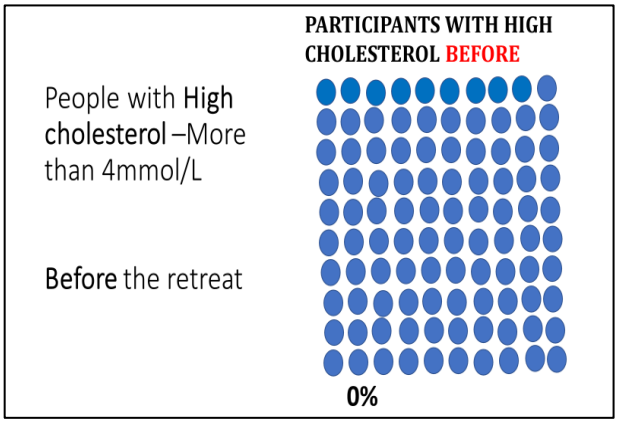


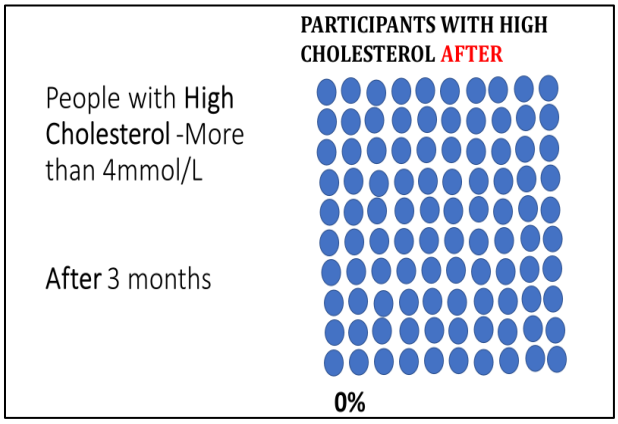
High HbA1C

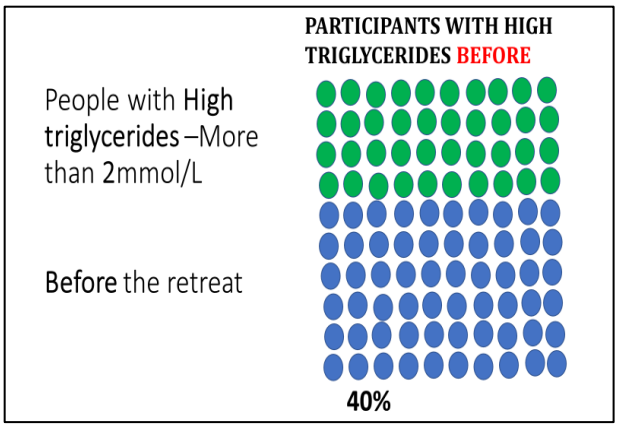


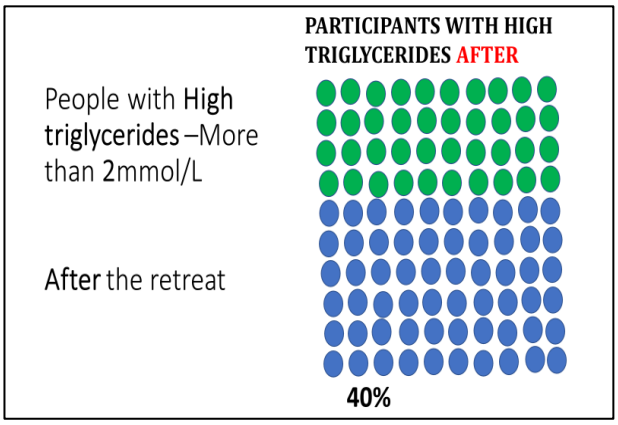


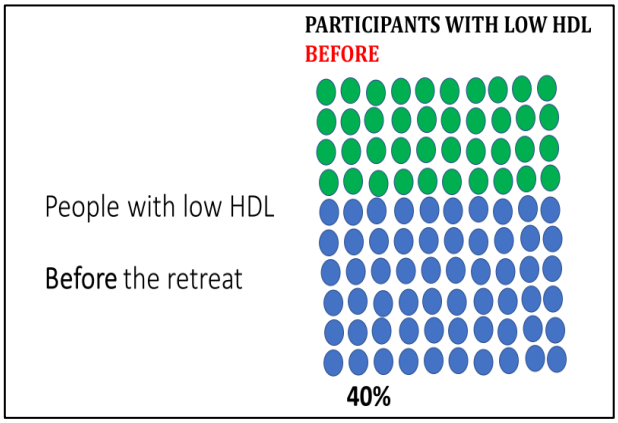
Cholesterol and lipids

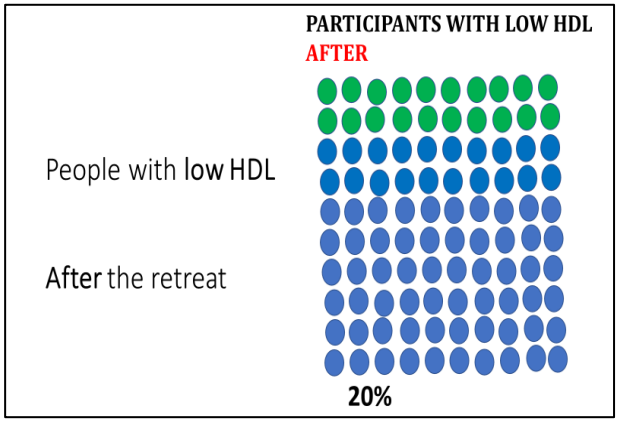


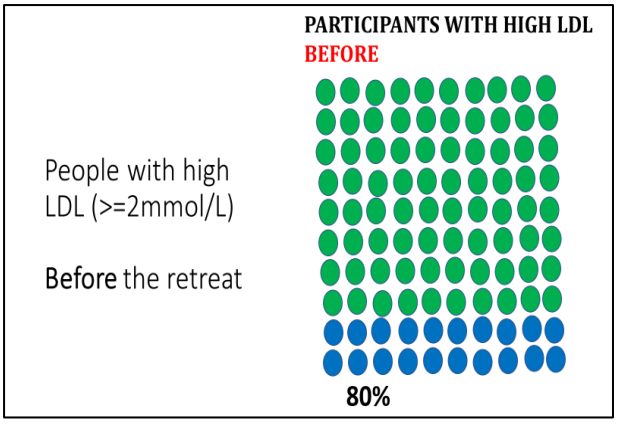


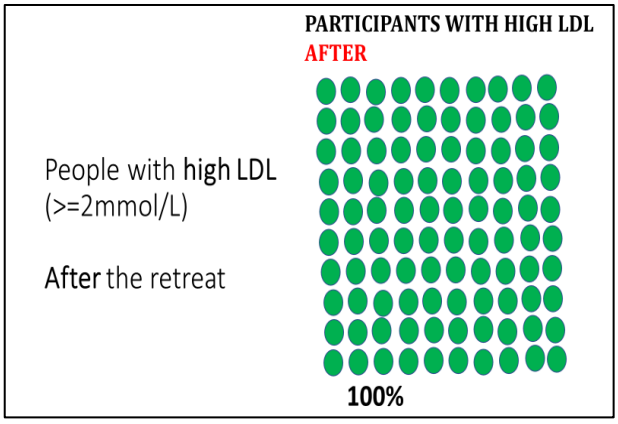

PARTICIPANTS WITH HIGH TRIGLYCERIDES BEFORE
People with High triglycerides –More than 2mmol/L
Before the retreat
40%


PARTICIPANTS WITH HIGH TRIGLYCERIDES AFTER
People with High triglycerides –More than 2mmol/L
After the retreat
40%


PARTICIPANTS WITH LOW HDL BEFORE
People with low HDL
Before the retreat
40%


PARTICIPANTS WITH LOW HDL AFTER
People with low HDL
After the retreat
20%


PARTICIPANTS WITH HIGH LDL BEFORE
People with high LDL (>=2mmol/L)
Before the retreat
80%


PARTICIPANTS WITH HIGH LDL AFTER
People with high LDL (>=2mmol/L)
After the retreat
100%

Discussion

This is the first formal evaluation of the Hope for Health program. We found that taking part in the program resulted in a significant decrease in waist circumference when comparing baseline measurements to three months post retreat, and a significant decrease in mean weight during the retreat. These results were particularly apparent for first time participants and may be because local staff and committee members took part in the retreat and do not represent the baseline of the participants from the community, and as a result are masking positive outcomes of the primary, first time participants. No significant change in clinical biomarkers including blood pressure, fasting blood glucose, HbA1c or cholesterol and lipid concentrations were demonstrated. However, the limited data for first time participants is favourable, suggestive of positive clinical outcomes

Key limitations of this evaluation were the small numbers analysed, particularly the clinical biomarkers involving blood collection, limiting the ability to prove statistical significance for the clinical and biomarker outcomes. In addition, the measurement of dietary patterns through questionnaire as opposed to direct observation may have resulted in recall bias. Selection bias may have also occurred with participants who returned for follow up evaluation at three months post retreat. In addition, incomplete data was available on participants medical history (number of diabetics, hypertensives and number who stopped and restarted medications) making it difficult to interpret the blood pressure, fasting blood glucose and HbA1C data.

During the retreat it was noted that several participants travelled into town and deviated from the recommended diet (including consumption of biscuits), which may have resulted in elevated fasting blood glucose levels at the end of the retreat. Evaluation of the program in a randomised controlled trial, with a larger sample size, longer follow up time, and directly observed measurements of dietary patterns is recommended.

Discussion/ TEAR evaluation

Discussion

‘What do Hope for Health people need to do to make real change?’

In reflecting on the retreat, and considering the question *‘What do Hope for Health people need to do to make real change’* Joanne Garŋgulkpuy named two logics which she sees as present within the Hope for Health program.

The first of these is a ‘logic of must’ that is associated with how Yolŋu must act and behave in accordance to the law. Following traditional practices and ancestral law, there was always clear direction around the collecting and preparation of foods. Following the law provided stories about how, when and where food should be eaten, by whom it should be prepared and how it should be shared. Garŋgulkpuy suggests that if the ‘logic of must’ was followed, Yolŋu would be hunting, collecting shellfish and eating traditional foods all the time.

The second is a ‘logic of choice’ that arrived with Balanda and is associated with their foods and health practices. This is very different to the ‘logic of must’ and involved Yolŋu in not only learning about Western foods and health practices, but also needing to operate as a particular kind of autonomous figure, making choices between good and bad foods that are available in the store or around the community.

She suggests that the work of Yolŋu these days is about finding ways to navigate and fit in with these logics of ‘must’ and ‘choice’. This is more complex than accepting and enacting just one particular route to health, but this is about understanding that there are differing ways that ‘health’ is constituted, and these processes themselves can be variously important or dangerous for Yolŋu in Galiwin’ku.

It is not possible to return exclusively to traditional foods, ways of life and relations to place in enacting a ‘logic of must’. But at the same time, working with a ‘logic of choice’ is a new and different relationship to health and well-being, involving sets of practices that can be exciting to learn as well as challenging to sustain.

When describing these processes, Garŋgulkpuy suggested that the metaphor of a bridge connecting two sides of the river is one possible way of thinking about working with these logics. However, this approach tends to miss the importance of place, or of Galiwin’ku, in talking about health. The story of different waters coming together in place, first becoming turbulent as they collide, and then settling to become calm as they mix together might be more useful for Hope for Health, and Yolŋu looking to find ways of navigating different practices of health, and ways of productively living with Western foods in the process of maintaining and strengthening a Yolŋu way of life (see Buthimaŋ, 2008 https://www.cdu.edu.au/centres/yaci/pdf/Buthimang_Gularri.pdf).

Perceptions of the process of change

Most of the Yolŋu participants that we spoke to had understandings of the relation between diet and health that conform reasonably closely to biomedical understandings. Participants described feeling

'fresh' and spoke about having more energy for activities and walking. For some this is described as 'feeling good inside and out'. They also talked about outcomes such as decreases in blood sugar levels and significant weight loss amongst participants.

For many, the health problems currently experienced by Yolŋu participants were also recognised as an effect of eating Western foods ('foods owned by others'), and traditional eating and food gathering and preparation practices were seen as significant to the task of finding a way out of the problems produced by unhealthy foods and eating practices.

In aligning food choices with a traditional Yolŋu (hi-fat, low carbohydrate) diet, Hope for Health supports a synergy between Yolŋu and biomedical understandings of health. This might be further explored in relation to comments made by some participants, that practices of hunting and food collecting associated with a Yolŋu diet could be further expanded within the conduct of the retreats. Including remembering that all Yolŋu foods have stories that describe how they should be gathered and prepared, and which connect Yolŋu people to the seasons, and/or supporting a return to a collective semi-ritualised preparation of store-bought food and the telling stories about this food, its origins, and its preparation, its benefits and distribution.

Valued Supports

Participants saw the support infrastructure offered by the broader Hope for Health program as valuable and beneficial.

Retreat organisers and healthcare professionals: Were seen as providing access to new knowledge of biomedical health, and ways to measure the effects of changing eating habits. Particularly including:

- Learning which Western foods are healthy and which are not
- Ways to discern and plan for this when shopping or cooking meals
- Feedback on health gains via blood sugar monitoring
- Weight measurements
- New literacies around medication and food supplements

Hope for Health Galiwin'ku based staff: Were recognised as offering valued on-ground support on an everyday basis through their cooking programs and house visits. These visits offer a way of keeping the program connected to Galiwin'ku through supporting the growth of strong community relationships and networks. These staff assisting with various elements of home life, including cleaning, which they describe as important to health and hygiene, and support intergenerational aspects of the project by involving young children in cooking sessions at home and on the beach. There were some concerns amongst the Steering Committee that these workers were not always adequately remunerated for their efforts.

Local Health Coach: Along with the Yolŋu Hope for Health staff, the local health coach was recognised as a crucial and valuable support in Galiwin'ku. This coach is well trusted by all Hope for Health participants, and through his own passion for the job and the place, is able to find ways to keep relevant and alive the health journey of many Yolŋu involved in Hope for Health. This role enables connections between traditional practices of Yolŋu hunting and food preparation to sit alongside and be complemented by other western understandings of health, doing so in ways that extend Yolŋu

aspirations to remember and maintain traditional practices as an element of producing healthy living practices.

Wider Community Engagement

Talking to participants about recent and past retreat attendance shows participation as tending to spread through family groups. Those who attend often feel safe to do so because of the presence of clan/family members, or because they have been told about it by clan/family members that have already attended retreats.

In line with this, it seems to be a clear strength that the program does not simply adopt 'whole of community' coverage as a measure of success, but rather aims to grow gradually through clan and family networks. Paying attention to the importance of 'witnessing' appears to assist with this process. Retreat participants spoke of 'seeing the evidence' of Dianne Biritjalawuy's return to health by changing her diet, and of needing to experience for themselves 'tasting a drink that was not soft drink, but still good.'

There are good connections between Hope for Health and other organisations and service providers in the community, including the clinic (Miwatj Health) and the store (ALPA). At present, programs tend to focus on changes in behaviour, attitudes and habits of individual participants, however through greater community engagement more broad scale supports for change may be possible. (For example, in Kalkaringi the local corporation is working with the store to subsidise the ingredients of one healthy meal a week. This brings the costs of selected ingredients to almost nothing, and supports interested people/families to learn a new recipe every week).

Program Sustainability

Hope for Health has been able to achieve substantial gains while working with tight funding arrangements, and the ongoing need to find new sources of revenue. It is possible that the need to obtain funding has in part driven decisions about program design. With recent changes in management, greater control is being vested in the Yolŋu Steering Committee, and there are opportunities for more significant co-design processes moving forward.

It is the opinion of many steering committee members and participants, that in order to achieve lasting health outcomes in Galiwin'ku the program needs to work and achieve outcomes within the community, rather than by processes that involve leaving the community and returning.

This is consistent with our observations that a program design that seeks to *bridge* between Yolŋu and Western understandings and practices of health, struggles to maintain legitimacy within both these arenas at the same time. However, with a foundation in Yolŋu practice as a means to then negotiate proper and correct understandings of how to understand and relate to Western foods, offers a better chance at long-term social and economic sustainability for the program and a healthy community.

Health Practices in Place

Careful learning and individual work done by Yolŋu at the retreat and afterwards, was seen by participants as important work leading to the development of a healthy community. This was in relation to their own changed practises and their ability to tell stories about food to their families.

Becoming stronger and more active, allows senior people and other Yolŋu to look for appropriate ways to support family, and strengthen community, through gurruṯu (kinship relations), which is seen as the appropriate pathways to meaningful change.

Participants credited their clearer understandings of what is in foods, medicines and natural supplements as bringing the benefit of improved doctor/patient relations at the clinic in Galiwin'ku, as they began to experience greater autonomy and control over their engagements with the mainstream medical system.

A key outcome for many of the retreat participants was an interest in teaching their new understandings and health practices to their children and grandchildren. By relating Yolŋu and Western practices of food preparation and eating, ways of teaching young Yolŋu also begin to include learning about Western foods – what is healthy and what is not.

It was expressed by many participants that the purpose of becoming healthy was to support the younger generation, both through having people in the community well enough to take up their role as leaders and educators, but also through developing role models and the capacity to share new knowledges and understandings with children and grandchildren.

> *This is a turning point for our children. Have to say 'You stop' because we have been going through this and want you to turn and have long ago what people used to have in that system eating well together. Still have to train them, teach them, train them and give our knowledge back to them. There is not many old people left.*

TEAR non-program specific evaluation questions

To assist with the assessment of TEAR Australia's international program and its underlying Theory of Change, all evaluations funded by TEAR are asked to answer the following additional questions and provide a score out of 10. The Evaluation considers at least two scores: one from the Evaluator, and one from another key stakeholder.

For the purposes of this assessment, scores and commentary have been provided by Joanne Garŋgulkpuy (Hope for Health Steering Committee member) as a stakeholder, and the Ground Up team as evaluators.

1. **Partnership**
    a. **How well has TEAR supported Hope for Health to become a more capable and effective organisation? Evaluator: 9 / 10 Stakeholder: 9/10**
    b. **What has been the most significant way that TEAR has supported Hope for Health**

The Yolŋu Steering Committee experienced TEAR as a very supportive organisation. This was particularly in the early stages as they carefully talked through the Hope for Health/ TEAR collaboration. Beyond this, TEAR have supported through offering funding, patience and understanding, communication, commitment and interest. As well as supporting the evaluation process and financial reporting to promote transparency, accountability and review of sustainability.

2. **Linkages**

    a. **To what extent are the communities involved in the project able to link with, and access resources from, other agencies and actors in their area? Evaluator: 7 / 10 Stakeholder: 6 /10**

    b. **What are some examples of how this is occurring?**

There was a sense that initially some of the relationships with other organisations were not fully visible to the Steering Committee. However, this now seems to be changing. Why Warriors Org has partnerships with ALPA and Miwatj Health that enable a focus on nutrition and health monitoring. There is also support from Why Warriors Pty Ltd in providing cultural resources and expertise. Community members benefit from these partnerships as well as the support from Galiwin'ku Council to access facilities for cook ups, cooking classes etc. There may be potential to continue strengthening these relationships – and a mutual flow of ideas between partners – over time.

3. **Rights**

    a. **How aware are the communities of their rights? Evaluator: 7/10 Stakeholder: 7/10**

Since the departure of the interim CEO and during the Retreat Assessment process, community members have become more conscious of their rights and responsibilities, particularly in governance. The Steering Committee is exploring their terms of reference with support from the Health Coach Mentor using the Australian Indigenous Governance Institute Toolkit and a collaborative painting developed during the retreats. Reviews have identified a need to improve communication between the board and Steering Committee, as well as a need for deeper co-design and co-planning of the program going forward. Steering Committee members have identified a desire to embark on a five year strategic planning process

    b. **How successful are they in turning their awareness of their rights into advocating for, and accessing what they are entitled to? Evaluator: 6/10 Stakeholder: 6/10**

There are significant barriers for Yolŋu with language, culture, written documentation and technological processes. In face to face consultation situations, Yolŋu are very clear in stating their requirements, preferences and concerns. In their daily lives they are all experienced in managing complex situations with various agencies (health, telecommunications, council etc.) as well as family so they are extremely capable people dealing with complex and intractable problems in their community. They are successful in communicating but not always in achieving what they are entitled to, largely due to external factors. For Garŋgulkpuy, this right includes being able to assert the right to choose 'the must' and to enact Yolŋu forms of living and family life as a basis for decision-making and growth over time.

4. **Long term problem solving**

a. **To what extent are communities able to solve their own development problems in creative ways? Evaluator: 9/ 10 Stakeholder: 9/10**

b. **What examples are there of communities taking initiative to solve their own problems in diverse and relevant ways?**

This whole program is an example of taking initiative, however requires significant resources to consolidate better practices in community and home life. This is the focus of 2020.

Galawarra, Elcho Island