

# Evaluation of the National Trachoma Health Promotion Programme

Report for Indigenous Eye Health University of Melbourne

Ninti One Limited



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Research and research support team

#### Ninti One Limited

Tammy Abbott, Senior Research Officer Sharon Forrester, Senior Community Research Officer Maureen Abbott, Aboriginal Community Researcher Lena Taylor, Aboriginal Community Researcher Elaine Williams, Aboriginal Community Researcher Samantha Cook, Aboriginal Community Researcher Kelly Swan, Aboriginal Community Researcher Robert Hoosan, Aboriginal Community Researcher Steve Fisher, Technical Advisor Laurie Berryman, Program Manager, Remote Community Research Angus Thornton, Program Manager, Remote Community Research Teghan Collingwood, Research Assistant

Project sponsors and support Indigenous Eye Health, University of Melbourne

Professor Hugh Taylor AC, Harold Mitchell Professor of Indigenous Eye Health Ms Fiona Lange, Health Promotion Project Officer Ms Emma Stanford, Research Fellow Dr Carol Holden, Senior Research Fellow Ms Emily O'Kearney, Research Assistant Ms Georgina Phillips, Trachoma Health Promotion Coordinator

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#### Contributing communities

Ninti One and Indigenous Eye Health at the University of Melbourne would like to thank all the individuals from the six participating communities for their input into this evaluation. The participating communities in alphabetical order were:

- Northern Territory: Ali Curung, Finke (Aputula), Lajamanu, Ntaria (Hermannsburg)
- South Australia: Pukatja (Ernabella)
- Western Australia: Warburton (Mirlirrtjarr)

#### For additional information please contact

Ninti One Limited Program Manager, Remote Community ResearchPO Box 3971, Alice Springs NT 0871, AustraliaTelephone: 0409 855 282Email: laurie.berryman@nintione.com.auwww.nintione.com.au

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# **Evaluation of the National Trachoma Health Promotion Programme**

**Report for Indigenous Eye Health** 

**University of Melbourne** 

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## **Executive summary**

Ninti One was invited by Indigenous Eye Health (IEH) to conduct an evaluation of the Trachoma Health Promotion Programme (THPP).

The project evaluated the work of IEH at the University of Melbourne and its contribution to the goals of the National THPP in six remote Aboriginal communities in Central Australia (namely the tristate border region of South Australia, the Northern Territory and Western Australia).

The intent of the project was to identify community knowledge and perceptions of the THPP and what impact this knowledge had on the respondents and their actions. The outputs will be used by IEH and others working in this field to continue the work of eliminating trachoma and to improve and develop future activities and initiatives.

Ninti One received approval from the Central Australian Human Research Ethics Committee (CAHREC) for this project.

The research was conducted over six locations – Ali Curung, Finke, Lajamanu, Ntaria, Pukatja (Ernabella) and Warburton – ensuring that a sufficiently large and representative sample of people was reached in each community and overall across the population.

It was also agreed the research team would conduct an average of 25 individual surveys and two focus group sessions in each of the six target communities. The research was designed to focus on the following themes:

- 1. the level of awareness of THPP messages
- 2. the means by which awareness has been achieved
- 3. the actions that people have taken as a result of their awareness.

Using these themes, a series of questions were designed for the Ninti One research team to utilise in conducting surveys and focus groups in each community.

A team of Ninti One researchers consisting of a Senior Aboriginal Research Officer and Aboriginal Community Researchers visited each of these communities. The initial visit introduced the project and allowed the team to identify local assistance and to ensure that local people were comfortable with the process. The same team conducted face-to-face interviews and focus groups on subsequent visits.

The interviews and focus groups were conducted in Arrente, Pitjantjatjara or English, depending on the preference of the participant. In total the researchers conducted 182 individual surveys and 10 focus groups across the six communities.

It is not possible to do justice to the insights and trends highlighted by this project in this summary. They can be read in detail in the data analysis section and in the conclusion. The key points of note include the following:

- The level of engagement of community members with the THPP is high, this being reflected in the level of recognition and responses, ideas and suggestions that community members provided.
- Recognition of Milpa varied to some degree across the communities, but there is a high level of recognition of the messages being promoted by THPP among the people who participated in the research.

The data showed that:

- 77% of people had seen Milpa
- 75% knew that Milpa meant good hygiene/faces/eyes
- 73% of people see Milpa and think of eyes/faces
- 86% understand what Milpa is saying.

Few people appear to understand that trachoma is a transmittable disease, with many believing it is attributed to bush living conditions.

Nobody objected to Milpa or the THPP messages, although they proposed ways to improve the impact of the messages and visits.

Over half (77) of the respondents indicated there is nothing stopping them from 'keeping faces clean', and of the categories indicating a barrier, 'no running water' or 'no hot water' were the most frequently cited and affected 23 people.

Community respondents freely contributed practical suggestions and ideas for improving the impact of Milpa's message, from the way information is shown on TV to the kinds of events that would make the greatest impact and the names that could be used for Milpa locally.

They offered a wealth of comments, indicating that people notice and care about health promotion. It also shows that community people will respond openly and clearly if asked in the right way and in a setting that suits them. The Aboriginal Community Researcher teams have been crucial in gaining the information that we have secured through this evaluation.

# 1. Introduction

## 1.1 Objectives

The purpose of this report is to describe the process and results produced by Ninti One through research to support an evaluation of the National Trachoma Health Promotion Programme (THPP).

The purpose of the research is to develop and deliver an independent evaluation of the National THPP in remote Australian communities.

The specific objectives of the work this document reports on are to assist Indigenous Eye Health (IEH) to develop a good understanding of:

- Which THPP messages are working: Are people seeing/hearing the messages? Where and when are they seeing the messages? What is their understanding of the message(s)? Are the messages making any difference? What is the level of intention to change behaviour?
- 2. What else can we do to make the messages more impactful or to change the social norm (do people understand that dirt on the face is a bad thing?)?

The objectives were proposed to be achieved by:

- submitting an ethics application to the Central Australian Human Research Ethics Committee (CAHREC) outlining the project, by June 2016
- conducting consultations including focus groups and interviews in six remote communities, by the end of March 2017
- providing IEH with a preliminary summary of results from completed communities at the end of November 2016
- preparing a draft report on the results obtained from consultations in all six communities by the end of April 2017
- finalising the report in consultation with IEH, by the end of June 2017.

In summary, the project evaluated the work of IEH at the University of Melbourne and its contribution to the goals of the National THPP in six remote Aboriginal communities in central Australia (namely, the tristate border region of South Australia, the Northern Territory and Western Australia). The outputs of this work will identify community knowledge and perceptions of the THPP and will be used by IEH and others working to eliminate trachoma to improve and develop future activities and initiatives.





Figure 1: Newsletter and drawing from Ntaria Childcare

# 2. Monitoring and evaluation strategy

## 2.1 Research focus

Ninti One was invited by IEH to propose how best our organisation could contribute to the evaluation of the THPP. Our starting point and first consideration was the impact measures defined by the evaluation framework for the work.

We agreed a process with IEH in which the Ninti One research team would conduct an average of 25 individual surveys and two focus group sessions in each of the six target communities. The research was designed to focus on the following themes:

- 1. the level of awareness of THPP messages
- 2. the means by which awareness has been achieved
- 3. the actions that people have taken as a result of their awareness.

Using these themes, we organised a series of questions for surveys and focus groups.

Ninti One and IEH agreed on six locations for the research to be conducted: Ali Curung, Finke, Lajamanu, Ntaria, Pukatja (Ernabella) and Warburton, ensuring that a sufficiently large and representative sample of people was reached in each community and overall across the population.

## 2.2 Co-design workshop

The evaluation was preceded by a one-day co-design workshop in Alice Springs involving IEH project staff and the Ninti One team (including Aboriginal Community Researchers), which resulted in field methods and questions being agreed.

In addition to the co-design workshop, a teleconference was held between IEH staff and Ninti One on 2 November 2016, in which an update on the research was discussed and IEH provided guidance around the final phases of the research.

Ninti One prepared a project plan that set out the key parameters of the work, deadlines and milestones to guide the project team.



Figure 2: Participants in the Trachoma Evaluation co-design workshop

## 2.3 Ethics approval

Ninti One applied for ethics approval to CAHREC for consideration at their meeting on 21 July 2016 and received conditional approval on 10 August 2016. The approval of CAHREC required only one change:

At Q 14 the data are not NID - please review your answer to this question.

Following our response to satisfy the alteration requested, final approval was granted by CAHREC on 20 September 2016.

## 2.4 Recruitment of research team

The Ninti One research team for this project comprises existing Senior Research Officers Tammy Abbott and Sharon Forrester and Aboriginal Community Researchers Maureen Abbott, Lena Taylor, Elaine Williams, Samantha Cook, Kelly Swan and Robert Hoosan. The project was managed and supported by the Ninti One Project Manager, Laurie Berryman, working in close consultation with the researchers.



Figure 3: Maureen Abbott, Aboriginal Community Researcher, conducting a focus group discussion in Lajamanu

# 3. Research process

## 3.1 Communities visited

During the period August 2016 to April 2017, our research team worked in the following communities:

Ali Curung	1 focus group (RJCP), 13 September 2016 1 focus group (Safe House), 6 October 2016 33 individual surveys, 6 October 2016
Finke	1 focus group, 11 September 2016 1 focus group, 10 October 2016 14 individual surveys, 12 September 2016 13 individual surveys, 11 October 2016
Ntaria	<ol> <li>focus group (Community Group), 15 September 2016</li> <li>focus group (Rangers), 10 October 2016</li> <li>focus group (Red Sandhill), 16 November 2016</li> <li>individual surveys, 10 October 2016</li> <li>individual surveys, 15 November 2016</li> <li>individual surveys, 16 November 2016</li> </ol>
Lajamanu	<ol> <li>focus group (Early Learning Centre), 22 September 2016</li> <li>focus group (Childcare Centre), 20 October 2016</li> <li>individual surveys, 19–20 October 2016</li> </ol>
Warburton	1 focus group, 23 November 2016 35 individual surveys, 22–23 November 2016
Pukatja	1 focus group (Art Centre), 22 February 2017 35 individual surveys, 22 February and 6 April 2017
Total	182 individual surveys and 11 focus groups

## 3.2 Participants

In each of the communities, the Ninti One team identified and obtained consent from the individuals for their participation in the research either as individual survey participants or as members of focus groups. Each participant was provided with an information sheet with the consent form that told them about the project, outlined their rights and how confidentiality and data storage would be managed and noted that the research had ethics clearance (Appendix A).

All interviews commenced with introductions and discussion about the purpose of the project and the right of the individual not to participate, as well as details of confidentiality and use of the information generated. We sought permission to record the interviews.

The interviews were conducted in Arrente, Pitjantjatjara or English, depending on the preference of the participant. When a local language was spoken, the researchers provided interpretation into English where required to ensure clarity of understanding for all parties.

## 3.3 Openness of communities to the research

Generally the purpose of the research was understood and people were open and supportive. In some cases, they offered help to organise focus groups.

It can be difficult to get people together due to absences from the community for travel to town and other social commitments away from the community. We experienced this problem on two occasions and so had to spend extra time and effort finding the people we needed to participate.

The interviews progressed well, with no issues relating to the style or content of questions. The focus group discussions also went according to plan, with active participation and discussion taking place (see Appendix B).

## 3.4 Survey design

During the co-design workshop a series of questions was developed, discussed and agreed upon.

The follow diagram demonstrates the question flow and logic. A survey designed around these questions was developed that could be used on paper or on a tablet and made available to all of the researchers working on this project.

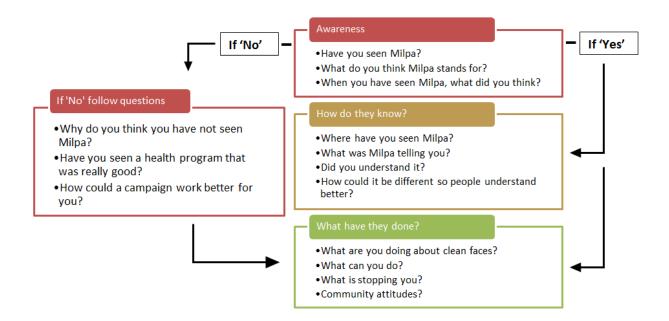
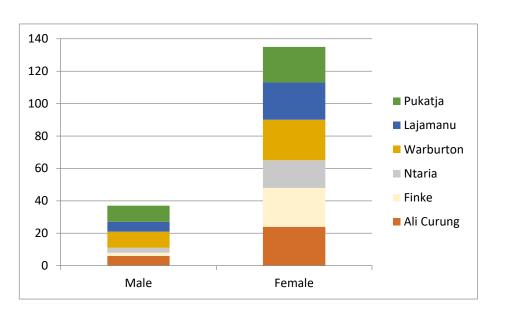


Figure 4: Survey design flow and logic

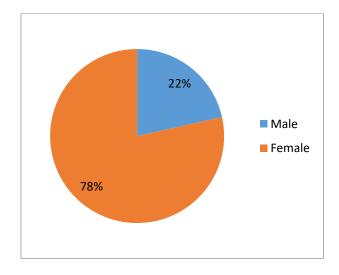
## 4. Data from survey questions

In this section, we present the data collected from the 182 individual surveys conducted. Comments and points of explanation are provided after each chart. Analysis of the data is presented in section 5.



## 4.1 Gender

Gender	Ali Curung	Finke	Ntaria	Warburton	Lajamanu	Pukatja	TOTAL
Male	6	2	3	10	6	10	37
Female	24	24	17	25	23	22	135



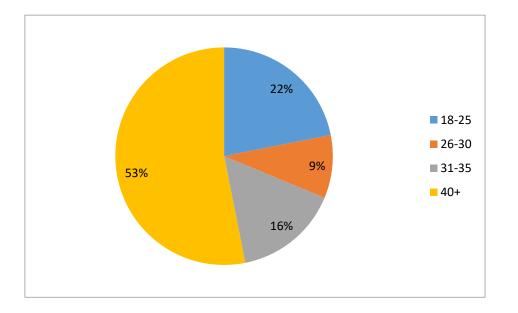
Dataset 1: Total gender distribution of participants (%)

Ten respondents skipped the gender question. Approximately four out of every five responding participants were women. The reasons for the imbalance are due to the different availability of women and men and the cultural factors restricting our predominantly female research team from interviewing men.

Also, the direct care and welfare of children is predominantly considered to be women's business within the communities that are the focus of this research. We will seek to increase numbers of men participating in the next phase of the research, although the factors above will make this aim a challenge.

Age range	Ali Curung	Finke	Ntaria	Warburton	Lajamanu	Pukatja	TOTAL
18–25	7	7	4	3	9	3	33
26–30	3	2	0	3	2	3	13
31–35	5	3	5	10	10	3	36
40+	17	15	11	18	8	24	93

## 4.2 Age range



Dataset 2: Proportion of participants in each age group (%)

Seven respondents skipped this question. The survey participants who did respond were not evenly distributed across age classes. Dataset 2 indicates an emphasis towards older parents and grandparents. It is also the case that no individuals in the 36–39 year age group participated, which was due to chance rather than any circumstances of which we were aware.

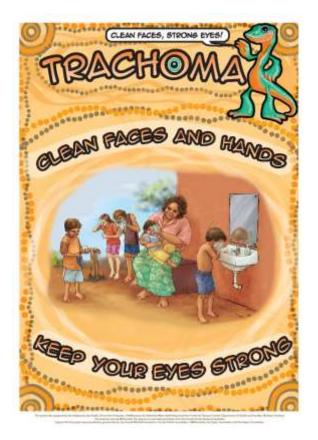
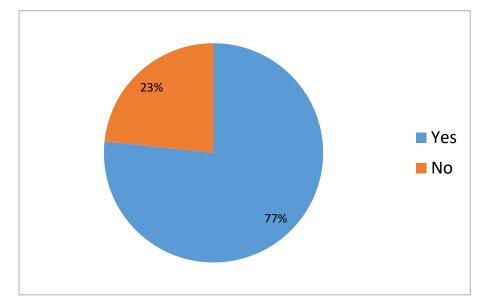


Figure 5: Trachoma poster

#### 4.3 Have you seen Milpa?

Have you seen Milpa?	Ali Curung	Finke	Ntaria	Warburton	Lajamanu	Pukatja	TOTAL
Yes	26	25	17	28	24	18	138
No	7	2	4	6	7	16	42



Dataset 3: Proportion of participants who reported having seen Milpa (%)

Two respondents skipped this question. More than four out of five respondents have seen Milpa across the five communities. The majority of respondents (77%) have seen Milpa, while 23% have not.

The lowest level of respondents having seen Milpa was from Pukatja, with nearly half of the Pukatja respondents indicating they had not seen Milpa.

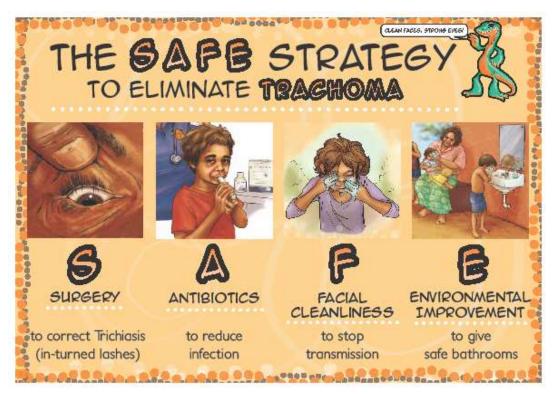
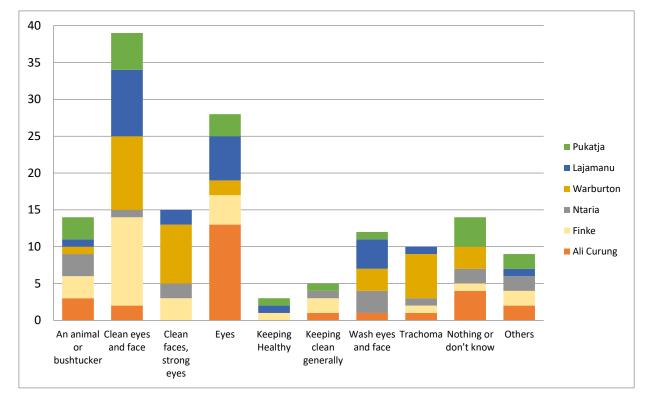
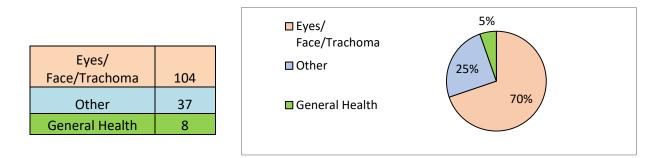


Figure 6: SAFE strategy poster

## 4.4 What does Milpa mean to you?

What does Milpa mean to you?	Ali Curung	Finke	Ntaria	Warburton	Lajamanu	Pukatja	TOTAL
An animal or bush tucker	3	3	3	1	1	3	14
Clean eyes and face	2	12	1	10	9	5	39
Clean faces, strong eyes	0	3	2	8	2	0	15
Eyes	13	4	0	2	6	3	28
Keeping healthy	0	1	0	0	1	1	3
Keeping clean generally	1	2	1	0	0	1	5
Wash eyes and face	1	0	3	3	4	1	12
Trachoma	1	1	1	6	1	0	10
Nothing or don't know	4	1	2	3	0	4	14
Others	2	2	2	0	1	2	9



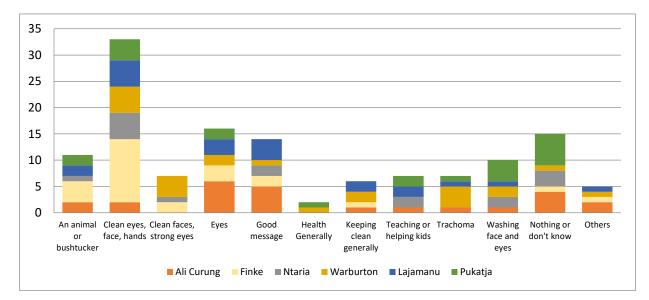


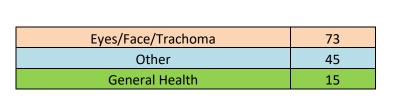
Dataset 4: Categorised responses from 'what does Milpa mean to you?'

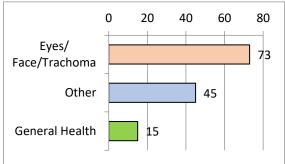
From this section on, datasets do not sum to 182 as respondents may have skipped a question or not had their answer fall into one of these categories, or may have had a response that could be categorised in multiple ways. The categorised responses were further grouped to demonstrate those that related directly to the Trachoma messaging, general health and other unrelated responses.

When you see Milpa, what do you think?	Ali Curung	Finke	Ntaria	Warburton	Lajamanu	Pukatja	TOTAL
An animal or bush tucker	2	4	1	0	2	2	11
Clean eyes, face, hands	2	12	5	5	5	4	33
Clean faces, strong eyes	0	2	1	4	0	0	7
Eyes	6	3	0	2	3	2	16
Good message	5	2	2	1	4	0	14
Health generally	0	0	0	1	0	1	2
Keeping clean generally	1	1	0	2	2	0	6
Teaching or helping kids	1	0	2	0	2	2	7
Trachoma	1	0	0	4	1	1	7
Washing face and eyes	1	0	2	2	1	4	10
Nothing or don't know	4	1	3	1	0	6	15
Others	2	1	0	1	1	0	5

#### 4.5 When you see Milpa, what do you think?





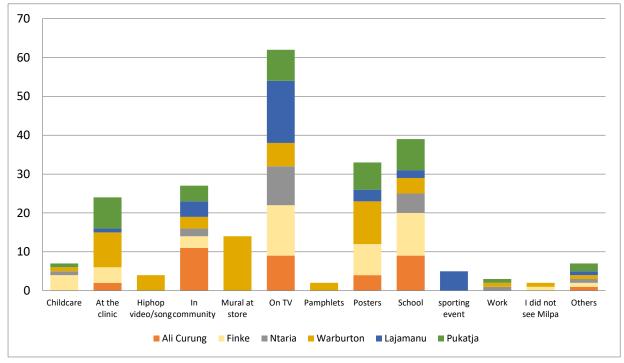


Dataset 5: Categorised responses for 'When you see Milpa, what do you think?'

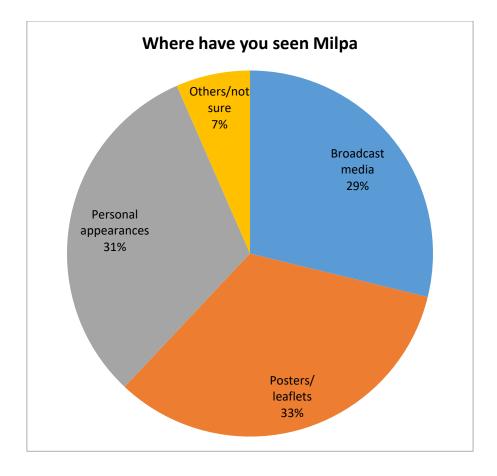
The responses to the preceding two questions are categorised in a way that brings out the key differences between them. We are interested in knowing how Milpa is perceived by participants in relation to health messages and exactly how these messages are interpreted. For example, the difference in a response that Milpa means 'eyes', which came from 28 people (shown in Dataset 4), is distinct from one in which Milpa means 'wash eyes and face', as indicated by 12 people (Dataset 4). The key difference is that the second response refers to Milpa being interpreted as requiring an action, in this case washing. The most commonly received response pertained to having clean eyes, faces or hands. Other frequent responses included 'eyes' and 'good message'.

Where have you seen Milpa?	Ali Curung	Finke	Ntaria	Warburton	Lajamanu	Pukatja	TOTAL
Childcare	0	4	1	1	0	1	7
At the clinic	2	4	0	9	1	8	24
Hiphop video/song	0	0	0	4	0	0	4
In community	11	3	2	3	4	4	27
Mural at store	0	0	0	14	0	0	14
On TV	9	13	10	6	16	8	62
Pamphlets	0	0	0	2	0	0	2
Posters	4	8	0	11	3	7	33
School	9	11	5	4	2	8	39
Sporting event	0	0	0	0	5	0	5
Work	0	0	1	1	0	1	3
I did not see Milpa	0	1	0	1	0	0	2
Others	1	1	1	1	1	2	7

## 4.6 Where have you seen Milpa?



Dataset 6: Categorised responses for 'Where have you seen Milpa?'

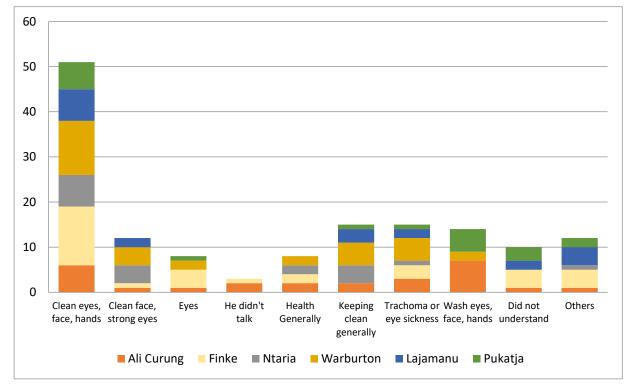


Dataset 6.1: Proportion of responses for 'Where have you seen Milpa?' according to the categories broadcast media, leaflets and posters and personal appearances of Milpa (%)

Categories of locations for this question are designed to make a distinction between broadcast media, paper-based media (leaflets and posters) and personal appearances of Milpa. If we aggregate the data according to these three categories, then we see the data above in a different way. According to the proportion of each category in Dataset 6.1, it is apparent that each medium of programme delivery has an approximately similar reach across the population we surveyed.

## 4.7 Did you understand what Milpa was telling you?

Did you understand what Milpa was telling you?	Ali Curung	Finke	Ntaria	Warburton	Lajamanu	Pukatja	TOTAL
Clean eyes, face, hands	6	13	7	12	7	6	51
Clean face, strong eyes	1	1	4	4	2	0	12
Eyes	2	1	0	0	0	1	4
He didn't talk	2	0	4	5	3	0	14
Health Generally	2	2	2	2	0	0	8
Keeping clean generally	0	0	2	0	0	1	3
Trachoma or eye sickness	3	2	3	0	0	1	9
Wash eyes, face, hands	7	0	0	2	0	5	14
Did not understand	1	4	0	0	2	3	10
Others	1	4	1	0	4	2	12



#### Dataset 7: Categorised responses for 'Did you understand what Milpa was telling you? If yes, what?'

The above question was worded ineffectively as it implies a yes/no answer; however, it did generate relevant responses in the form we were seeking. Important here, as was the case with earlier questions, is the difference between messages that show an understanding of change (such as 'clean eyes, face, hands') and those pointing to an action required (such as 'teaching kids' or 'keeping clean generally').

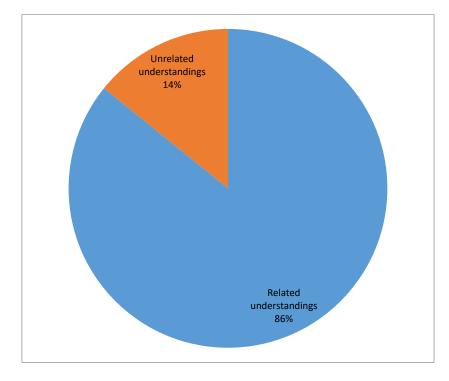
Responses categorised as 'others' comprised unrelated responses (4), general health messages (4), medication to improve eye health (1) and an acknowledgement of understanding the message without explaining what was understood (3).

As we will comment further in sections 5 and 6, another important distinction to be made is between responses that demonstrated an understanding directly related to the intended message (i.e by directly

referencing the need to wash faces to promote eye health) and those that did not. Dataset 7.1 displays the proportion of responses that are related to the intended message in comparison to those that are unrelated.

Summary of awareness and message recognition:

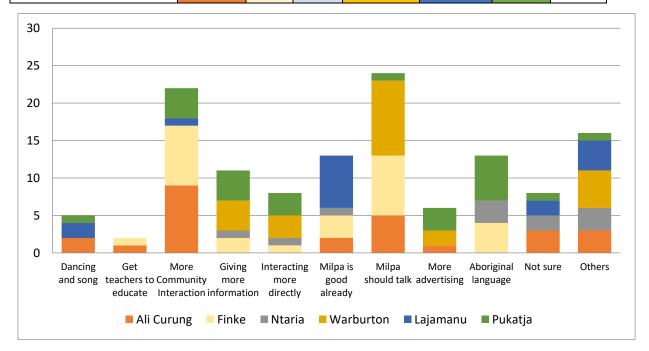
- 77% of people had seen Milpa
- 75% knew that Milpa meant good hygiene/faces eyes
- 73% of people see Milpa and think of eyes/faces
- 86% understand what Milpa is saying.



Dataset 7.1: Proportion of responses in question 'Did you understand that Milpa was telling you?' that are related or unrelated to the intended message (%).

## 4.8 How could people understand Milpa better?

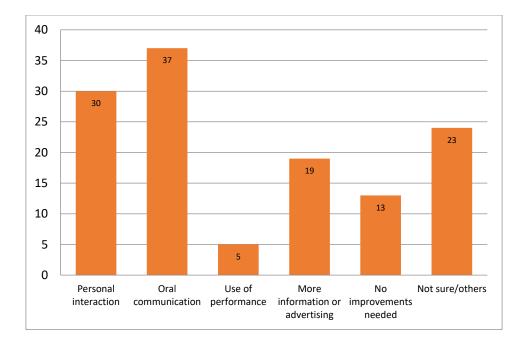
How could people understand Milpa better?	Ali Curung	Finke	Ntaria	Warburton	Lajamanu	Pukatja	TOTAL
Dancing and song	2	0	0	0	2	1	5
Get teachers to educate	1	1	0	0	0	0	2
More community interaction	9	8	0	0	1	4	22
Giving more information	0	2	1	4	0	4	11
Interacting more directly	0	1	1	3	0	3	8
Milpa is good already	2	3	1	0	7	0	13
Milpa should talk	5	8	0	10	0	1	24
More advertising	1	0	0	2	0	3	6
Aboriginal language	0	4	3	0	0	6	13
Not sure	3	0	2	0	2	1	8
Others	3	0	3	5	4	1	16



#### Dataset 8: Categorised responses for 'How could people understand Milpa better?'

Responses categorised as 'others' (16) include unrelated responses (11), showing bush tucker or medicine (2), through doctors (1), stickers (1) and animated cartoons (1).

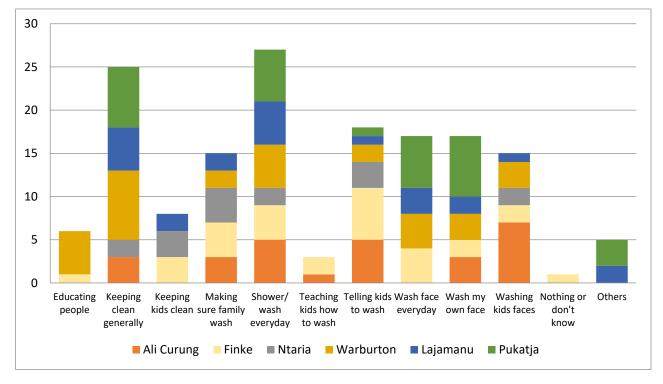
Although better grouped with the later questions on improving the program, this question brings out participant suggestions on ways messages could be better understood by the target population. Again, it is instructive to present the data in more than one way. Dataset 8.1 (below) categorises responses according to the types of suggestions participants made.



Dataset 8.1: Grouped responses indicating ways to improve communication and understanding of the programme message to participants.

## 4.9 What are you doing about clean faces?

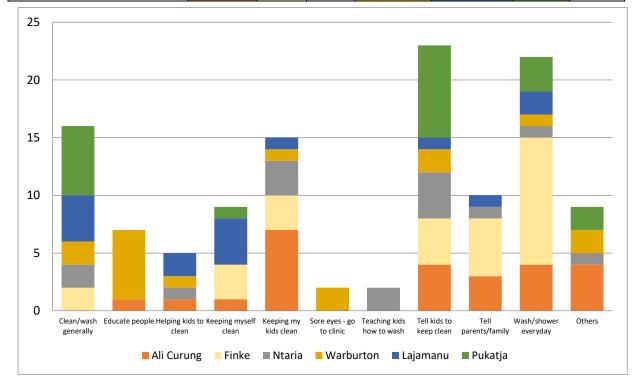
What are you doing about clean faces?	Ali Curung	Finke	Ntaria	Warburton	Lajamanu	Pukatja	TOTAL
Educating people	0	1	0	5	0	0	6
Keeping clean generally	3	0	2	8	5	7	25
Keeping kids clean	0	3	3	0	2	0	8
Making sure family wash	3	4	4	2	2	0	15
Shower/wash everyday	5	4	2	5	5	6	27
Teaching kids how to wash	1	2	0	0	0	0	3
Telling kids to wash	5	6	3	2	1	1	18
Wash face everyday	0	4	0	4	3	6	17
Wash my own face	3	2	0	3	2	7	17
Washing kids' faces	7	2	2	3	1	0	15
Nothing or don't know	0	1	0	0	0	0	1
Others	0	0	0	0	2	3	5



Dataset 9: Categorised responses to 'What are you doing about clean faces?'

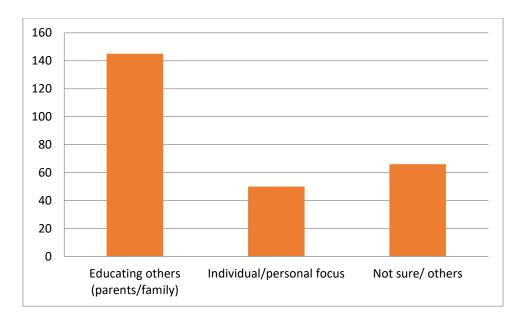
What can you do about clean faces?	Ali Curung	Finke	Ntaria	Warburton	Lajamanu	Pukatja	TOTAL
Clean/wash generally	0	2	2	2	4	6	16
Educate people	1	0	0	6	0	0	7
Helping kids to clean	1	0	1	1	2	0	5
Keeping myself clean	1	3	0	0	4	1	9
Keeping my kids clean	7	3	3	1	1	0	15
Sore eyes – go to clinic	0	0	0	2	0	0	2
Teaching kids how to wash	0	0	2	0	0	0	2
Tell kids to keep clean	4	4	4	2	1	8	23
Tell parents/family	3	5	1	0	1	0	10
Wash/shower everyday	4	11	1	1	2	3	22
Others	4	0	1	2	0	2	9

## 4.10 What can you do about clean faces?



Dataset 10: Categorised responses to the question 'What can you do about clean faces?'

The preceding two questions are similar in character and elicit similar sets of responses. A useful way of viewing the data is to note the difference between responses that suggest the person themselves is doing or will do something about clean faces, and those responses that emphasise the teaching and encouraging of other people, such as children or parents. This analysis is provided in Dataset 10.1 below.

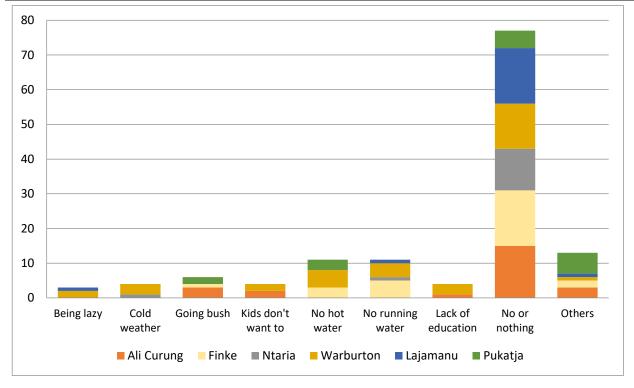


# Dataset 10.1: Aggregated responses according to theme for the questions 'What are you doing about clean faces?' and 'What can you do about clean faces?'

In Dataset 10.1, we have aggregated the majority of categories into new groups (educating others vs. individual behaviour change); however, for more general categories (i.e. shower everyday) the individual responses were reviewed to determine the appropriate new grouping. Ambiguous responses such as 'wash', which could pertain to washing children or themselves, were assigned to the 'not sure/others' category.

Does anything stop you from keeping faces clean?	Ali Curung	Finke	Ntaria	Warburton	Lajamanu	Pukatja	TOTAL
Being lazy	0	0	0	2	1	0	3
Cold weather	0	0	1	3	0	0	4
Going bush	3	1	0	0	0	2	6
Kids don't want to	2	0	0	2	0	0	4
No hot water	0	3	0	5	0	3	11
No running water	0	5	1	4	1	0	11
Lack of education	1	0	0	3	0	0	4
No or nothing	15	16	12	13	16	5	77
Others	3	2	0	1	1	6	13

#### 4.11 Does anything stop you from keeping faces clean?

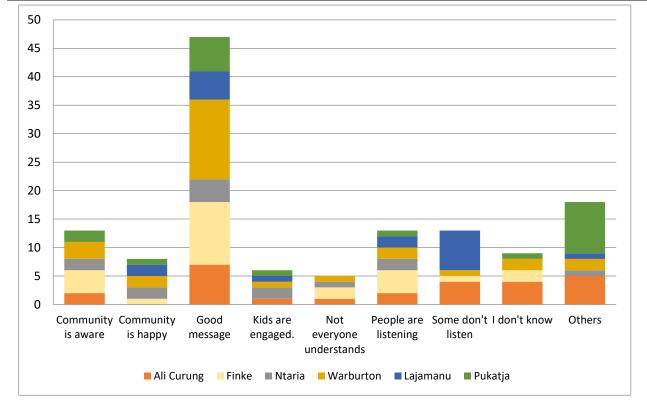


Dataset 11: Categorised responses for 'Does anything stop you from keeping faces clean?'

In response to the important question for the evaluation of whether anything prevents participants from keeping faces clean (summarised in Dataset 11 above), 77 of 133 participants indicated they faced no obstacles to keeping faces clean, while 45 participants said they do (with 43 participants indicating more than one reason). Of the eight categories indicating a barrier, 'no running water' or 'no hot water' are the most frequently cited, affecting 22 people. The 'others' category comprised unrelated responses (7), due to ceremony (2), sore eyes (1), sore shoulder (1), don't know (1) and dry skin (1).

## 4.12 How do the community feel?

How do the community feel?	Ali Curung	Finke	Ntaria	Warburton	Lajamanu	Pukatja	TOTAL
Community is aware	2	4	2	3	0	2	13
Community is happy	0	1	2	2	2	1	8
Good message	7	11	4	14	5	6	47
Kids are engaged	1	0	2	1	1	1	6
Not everyone understands	1	2	1	1	0	0	5
People are listening	2	4	2	2	2	1	13
Some don't listen	4	1	0	1	7	0	13
I don't know	4	2	0	2	0	1	9
Others	5	0	1	2	1	9	18



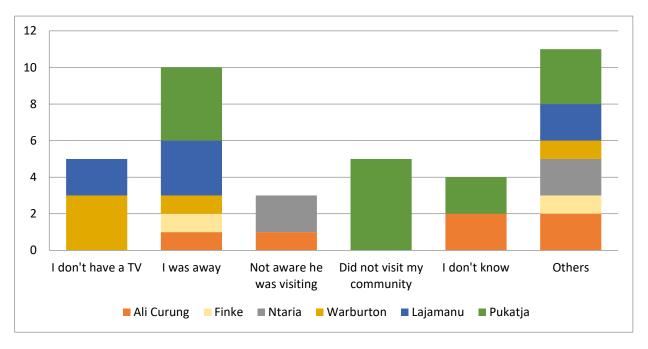
Dataset 12: Community attitudes to the programme categorised by theme and in response to the question 'How does the community feel (about the programme)?'

The responses to this question reveal its shortcomings in that 'good' is by far the largest response. We interpret 'good' to mean that the community is responding well to the programme and is supportive of the messages it delivers.

The negative responses imply a problem in the message being received and acted on. They show that not everyone hears or understands what Milpa is saying. These responses amount to 34% of the total (n=132), and are derived from the categories 'not everyone understands', 'some don't listen', 'I don't know' and 'others'. Responses categorised as 'others' (18) included unrelated responses (3), wanting to learn more (1), alright (1), uncomfortable (1), and for more people to come and visit (1), worried/fearful (3), unsure (3).

Why do you think you have not seen Milpa?	Ali Curung	Finke	Ntaria	Warburton	Lajamanu	Pukatja	TOTAL
I don't have a TV	0	0	0	3	2	0	5
I was away	1	1	0	1	3	4	10
Not aware he was visiting	1	0	2	0	0	0	3
Did not visit my community	0	0	0	0	0	5	5
I don't know	2	0	0	0	0	2	4
Others	2	1	2	1	2	3	11

#### 4.13 Why do you think you have not seen Milpa?

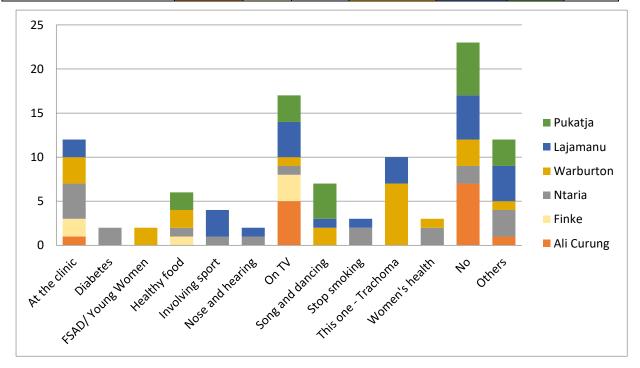


Dataset 13: Categorised responses for 'Why do you think you have not seen Milpa?'

The question about not seeing Milpa was aimed at participants who initially indicated that they were not aware of the programme through Milpa. The main responses show that participants were either away from the community during Milpa's visit or that they do not have a television. Responses categorised as 'others' comprised unrelated (7), didn't have time (1), living out bush (1), Milpa only goes to the school (1) and 'I heard he was at the oval' (1).

## 4.14 Have you seen a health programme that was really good?

Have you seen a health programme that was really good?	Ali Curung	Finke	Ntaria	Warburton	Lajamanu	Pukatja	TOTAL
At the clinic	1	2	4	3	2	0	12
Diabetes	0	0	2	0	0	0	2
FSAD/ Young Women	0	0	0	2	0	0	2
Healthy food	0	1	1	2	0	2	6
Involving sport	0	0	1	0	3	0	4
Nose and hearing	0	0	1	0	1	0	2
On TV	5	3	1	1	4	3	17
Song and dancing	0	0	0	2	1	4	7
Stop smoking	0	0	2	0	1	0	3
This one – Trachoma	0	0	0	7	3	0	10
Women's health	0	0	2	1	0	0	3
No	7	0	2	3	5	6	23
Others	1	0	3	1	4	3	12



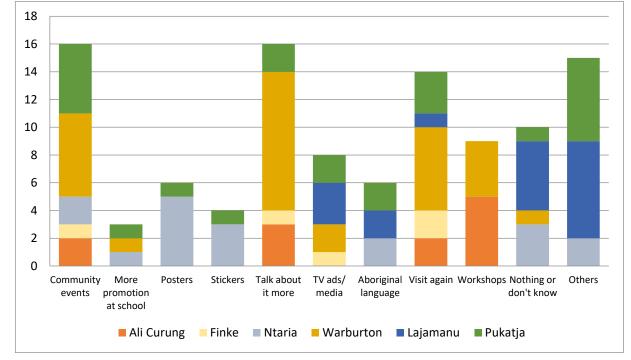
Dataset 14: Categorised responses for 'Have you seen a health programme that was really good?'

The question on whether participants had seen an effective health programme elicited many different responses. These results imply the need for further analysis of what makes a good health programme for those who responded by naming programmes but without our survey asking them to explain why.

Responses categorised as 'others' comprised 'yes' (2), cleaning the home (1), programmes at the school (1), programmes promoting school (1), how to look after children (1), other health promotion advertisements (1), foot and eye doctor (1), the Kalkaringi mob IHHP (1), mental illness (1) and unrelated (2).

How cold a campaign	Ali						
work better for you?	Curung	Finke	Ntaria	Warburton	Lajamanu	Pukatja	TOTAL
Community events	2	1	2	6	0	5	16
More promotion at school	0	0	1	1	0	1	3
Posters	0	0	5	0	0	1	6
Stickers	0	0	3	0	0	1	4
Talk about it more	3	1	0	10	0	2	16
TV ads/ media	0	1	0	2	3	2	8
Aboriginal language	0	0	2	0	2	2	6
Visit again	2	2	0	6	1	3	14
Workshops	5	0	0	4	0	0	9
Nothing or don't know	0	0	3	1	5	1	10
Others	0	0	2	0	7	6	15

#### 4.15 How could a campaign work better for you?



Dataset 15: Participant suggestions by category for the question 'How could a campaign work better for you?'

This question attracted 107 responses, 82 of which were suggestions of how the campaign could work better. The most common responses were 'community events' and 'talk about it more' both with 16 responses, followed by 'visit again' (14) and 'workshops' (9), all of which indicate respondents are keen to participate in face-to-face health promotional activities. The focus groups added further suggestions to this list.

The responses categorised as 'others' included unrelated (8), promotion involving AFL players (2), supporting the health clinic (1), home visits (1), more health programmes (1) and making soap with girls to promote clean hands (1).

# 5. Data analysis

In this section, we provide a summary analysis of the data from both the focus groups and surveys conducted. Since the questions about suggestions for ways to improve the programme were so productive in generating responses, we then go on to provide a full listing of those replies, grouped by theme.

## 5.1 Key insights

Recognition of Milpa is generally high across the communities. People in some communities show a higher level of recognition and understanding, while others show lower awareness of Milpa.

There is also some variation in knowledge within focus groups. Some groups have the majority of participants familiar with Milpa and his message, while other groups only had one or two participants showing awareness.

People have some practical suggestions and ideas for improving the impact of Milpa's message, from the way information is shown on TV, to the kinds of events that would make the greatest impact, and the name that is used for the goanna locally to make it more relevant and relatable.

Milpa and his message are better understood within the school-aged children demographic in comparison to adults. As indicated in the surveys, this is due to promotion aimed at children in school.

Participants appear to value the creative and performance elements of the THPP, with many mentioning aspects of song and dance, for example, that they like or wish to see more frequently in the programme.

## 5.2 Trends in the data

Recognition of Milpa is higher among women than men (although the sample size of men is small).

More people recognise the message and purpose of Milpa than know his name.

Milpa was often recognised initially in the context of an animal or bush tucker, with 9% of people relating to this component of the Milpa character. Despite this, there is also a 77% understanding that Milpa is associated with a message of having clean eyes.

Visits were frequently mentioned by participants across all communities as being important for Milpa to be seen and his message understood.

There is a tendency for some people to attribute trachoma to bush conditions (dust, smoke) rather than making the connection with dirty faces.

Very few participants appear to understand that trachoma is a transmittable disease.

Many people mentioned the importance of the role of parents in keeping children's faces clean.

Many people suggested that the message needs to go directly to small children and had suggestions for using existing methods in schools and childcare centres, for example, with puppets and using music and dance.

Nobody objected to Milpa or the message of THPP, although many would like to see improvements and made suggestions for ways to improve the impact of the clean faces message.

In each community there is a subset of the population who do not display interest in the programme, although this is a minority.

Creative mediums, particularly song and dance (but also cartoons, hip-hop videos and artwork) are viewed favourably across all communities to promote the campaign message:

They made a video here in Warburton, and it's being used around the [other] communities.

There was singing and dancing and the kids liked it; they all joined in.

Many people are interested in learning more about trachoma itself.

#### 5.3 Significant exceptions and outliers

In this section, we provide comments or responses that were infrequent but we consider represent views or observations relevant to the objectives of the research.

A small number of people mentioned access to water for washing as being an issue. Some limitations in facilities when camping and on homelands were the context in which this point arose. Cold weather was also mentioned by a small number of people as being a deterrent to washing faces.

Inadequacy of facilities in run-down housing was mentioned as a key barrier to keeping faces clean regularly, along with isolation and not having access to soap:

Housing is a big issue, maintenance is hard ... families lose motivation to keep trying to maintain and clean the house.

There was some discussion among participants about what animal Milpa is, which seemed to be a distraction from the message itself. For example, one person said:

I thought it was a croc, but it's a goanna.

Another said:

He's a gecko or a lizard.

The mural at the Warburton Store was associated with a high rate of campaign awareness and interest. It included images of two children from the community.

Some participants associated having sore eyes with the need to get eye drops/tablets from the clinic, without explicitly identifying that behaviour change (i.e washing faces) could be used as a preventative tool.

Recognition of Milpa is low at Pukatja, at just over half the respondents.

There is some interest in getting access to relevant statistics on trachoma in the community.

## 5.4 Ideas and suggestions

Many suggestions were made by participants and all are included here, except where they are repeated, in which case we denote in brackets the total number of similar comments (e.g. x3). They are grouped into themes.

#### 5.4.1 Football and other sporting events

Across all communities, football is an enjoyable community event. Accordingly, many participants suggested that football be used to enhance the promotion of the campaign:

Everybody loves footy; Aboriginal players like the Melbourne Demons on the posters should come to community and do activities to make the message strong.

The Finke Desert Race is a good time for Milpa to visit. The Demons players would be a great way of getting the message out, even though the community are Port Power and Adelaide Crows supporters.

Football is one of the greatest enjoyments in the community for all ages and genders, and the Melbourne Demons footy players could come and teach them stuff and tell them about clean eyes.

One participant said that even though having football players in the campaign would be a positive move, having them participate is not as important as having Milpa speak in language.

#### 5.4.2 The role of Milpa

One participant suggested Milpa take a more central position in television advertisements, rather than staying in the background:

They need to bring him out more, put him up front ... Put Milpa in front of the footballers.

Participants mentioned that Milpa should talk and this should be in the different languages relevant to each community or there should be an offsider who speaks local languages (x4):

They should put it in language so the mob can understand better.

He should talk language.

Milpa needs to talk in all languages. No good talking in English because you are trying to target people in communities. Put English in the background and use all kinds of different language so people can understand.

Milpa is viewed favourably by the children in communities, and should come more often to promote the message (x3):

Milpa has got to start visiting all these communities more often.

Milpa should not only visit the school, but move around all parts of the community to spread the message in a more demographically inclusive way:

The kids relate to it, but the Elders don't relate to it, because Milpa goes to the school.

It could be good to market it to adults. But not just with children's images, because when adults see Milpa they think it is just for children.

In Pukatja, it was suggested that the local word 'kuru' would be better to use than Milpa, which has no local meaning. 'Kuru' means 'eyes'.

#### 5.4.3 Broadcast and other media

One participant requested more frequent TV advertising.

It was mentioned that more posters should be in the community (x2).

Participants asked if Imparja TV could have more Milpa advertisements rather than NITV:

Not many people watch [NITV], but if you can get it on Imparja that would be good; most people watch that.

Participants agreed that animated cartoons in language would get children's attention (x2):

Cartoons! In language! You'll attract the kids straight away!

Promotion involving artwork is viewed positively:

The artwork is catchy; when I see Aboriginal art in posters, I take notice.

#### 5.4.4 Family and community events

One of the ladies suggested that Milpa could bring stickers or posters next time and then they could be taken out to the homelands to stick in the bathroom to assist parents in reminding their children to clean their faces.

People mentiond that hip-hop road shows and BBQs are a good way to share information and everyone can come.

Several suggestions were made for the clinic to be more involved in the campaign:

The clinic should get more involved and visit people to encourage them to get to their appointments, especially for those who don't attend.

Clinic should go to school and have an eye check-up day, or at the clinic with Milpa and footy players.

People said the school should check and encourage clean hands and faces (x2).

There were also suggestions to set up a money tin in a prominent location (i.e shop), with the proceeds going towards activity days where Milpa and football players come to promote the message.

Participants felt that Milpa needs to be more of a presence around the community, such as attending childcare and delivering his message to the little ones and their parents/carers. The children love interacting with big puppets:

Song and dance is a good way for our kids to learn and they like singing in Warlpiri.

It's good when they come into community.

In all communities, participants identified the importance of the family unit in promoting the Milpa message and also facilitating behaviour change:

Get families to talk to other families to help keep their kids eyes clean.

A family day with Milpa would be good for all the family to go to.

People also said that Milpa should do activities in places other than the school (e.g. bush trips) and demonstrate how to keep eyes clean when running water is not available (e.g. carry water and face washer).

# 6. Conclusion

Through the evaluation activities described in this report, many insights have been gained, both about the effectiveness of the messages transmitted by the THPP and how they can achieve greater impact. In the previous section we identified the key findings; trends in the data, exceptions and outliers; and ideas and suggestions made by the participants in the evaluation. To conclude, we offer a number of overall reflections on the findings.

In the first place, the level of engagement of community members with the THPP is higher than might have been expected from a reading of Ninti One's extensive research work on remote and desert services. During research conducted over more than a decade, we have observed that most settings in which Aboriginal people gain access to services put them in the role of passive recipients of a pre-determined and narrow set of options, as opposed to an active chooser of services.

Because the THPP is a health promotion programme rather than a service, it might be expected that people are less engaged with it than they could be and that it would be difficult to do an evaluation. We found the opposite. Many people who participated in this evaluation were forthright in their thinking and constructive in offering suggestions about the programme. Many people would like to see improvements and made suggestions on ways to improve the impact of the clean faces messages. They offered a wealth of comments. This indicates that people notice and care about health promotion. It also shows that community people will respond openly and clearly if asked in the right way and in a setting that suits them. The Aboriginal Community Research teams have been crucial in gaining the information that we have secured through this evaluation.

Second, there is generally a high level of recognition of the messages being promoted by THPP among the people who participated in the research. We are conscious of a potential bias in that the people who are more engaged in health promotion may have been the ones who offered themselves to participate in the research, as opposed to individuals who may have been unreceptive to health messages. The surveys and focus groups sought to gather community perspectives rather than to target families whose children were most vulnerable to eye infections.

Third, it is sometimes said that paper-based information has limited value in remote communities because many people are unaccustomed to holding paper and reading what is on it. Given the data we collected, this point clearly does not apply to the materials from the THPP, which rated equally highly in recognition to broadcast media and community visits as being effective means by which people recognise Milpa and the messages that accompany him.

However, it is important to note that people felt that Milpa could have a greater impact through personal interaction, that is, through workshops, visits and community events. Milpa may not have been described with affection in the way that a superhero might be, the Deadly Dan anti-smoking figure being a case in point, with his 'You smoke, you choke' message and cartoon book. But many people see the importance of the Milpa message. They are generally closely engaged in the subject of clean faces and healthy eyes and they appreciate the visibility that comes from a visit from Milpa.

Fourth, given the range of different suggestions we heard from participants in the research about ways to improve the impact of the messages, we are careful in offering general summation. We recommend that the reader should visit section 6 to gain a full picture of the subtle differences between suggestions. However, common themes in these suggestions relate to choosing the most effective role and location of Milpa when he visits the community, the way in which he interacts with children and their families and the

use of local languages. The last point includes the use of a meaningful local name, given that Milpa is not necessarily a recognisable word outside Warlpiri-speaking communities.

Finally, it is worth noting that any research conducted within a complex environment such as remote Australia presents challenges of many different kinds, including climate, distance, language, effective cross-cultural work and the need to work within community norms and protocols. We are pleased to deliver this report and appreciative of the opportunity to contribute to the THPP. We acknowledge in full the participation and support of many people in the communities in which we worked.

# **Appendix A: Participant Information Document**

This document was provided to each person approached to participate in this project.

# **Participant Information Document**

**Project title:** Trachoma Health Promotion Programme Evaluation

# This is for you to keep



Introduction to the project: Ninti One has been asked by the

University of Melbourne to look at what people know and remember about the trachoma health program activities which have been run in their community. We will mainly talk to people in small groups, but may also do some one-on-one interviews. Each of these talks may take up to an hour.

**Participant rights**: Being in this project is up to you. You can decide not to answer any questions at any time, you can without any trouble or shame, decide not to take part at all. If you decide to take part in the survey, you can stop at any time without any reason, and you can refuse to answer any of the questions. We will not ask why. We will delete your name and not use any of the information that you give us if you ask us to – right up to the final report being drafted.

By signing the attached Informed Consent Form, you are giving us the OK to use the information that you give us.

**Confidentiality:** No-one but the nominated researchers will have access to the raw information provided by the participants. We will record what community you live in, your gender and age range and no other identifiable information. We will not record anyone's names and we will not collect any information that will be able to easily identify the people who are part of this project. We will not use or publish your name or anything that will allow other people to know who you are from this research.

**Data Storage:** All data and information collected during this research will be stored in hard copy and digital form, in compliance with Ninti One's policy on safe storage, privacy and raw data management. Hard data will be kept in locked filing cabinets and access to digital data will be password protected. The data and information generated during the research will be destroyed after five (5) years.

**Ethics Committee Clearance:** This research project has been approved by an independent Human Research Ethics Committee (*the Central Australian Human Research Ethics Committee*) whose job it is to protect the rights of everyone who takes part in research.

#### Further information about the project (who to contact):

If you would like further information about the project, please do not hesitate to contact:

Tammy Abbott Senior Research Officer Ninti One PO Box 3971 Alice Springs NT. 0871 Tel No: 0437 312 134 Email: tammy.abbott@nintione.com.au

#### **Concerns and/or Complaints:**

Further requests for information or queries regarding this research project should be directed to the Project Manager Remote Community Research:

Laurie Berryman Ninti One PO Box 3971 Alice Springs NT. 0871 Tel No: 0437 312 134 Email: <u>angus.thornton@nintione.com.au</u>

If you have any concerns or complaints regarding the ethical conduct of the study, you are invited to contact:

Central Australian Human Research Ethics Committee C/- Centre for Remote Health Corner of Simpson and Skinner Streets (PO Box 4066) Alice Springs NT 0871 Tel No: (08) 8951 4700 Email: cahrec@flinders.edu.au

# Appendix B: Data from focus groups

## Ali Curung

#### Safe House Group

The participants were six female community members. Key insights (primarily emphasised by one participant) were for the Milpa campaign to be improved by considering the following:

- Including appropriate language (English not to be the focus)
- Cartoons and animations on TV would be effective for engaging children
- Footballers should not be featured as prominently as Milpa
- Speaking in language is more important than having footballers
- Milpa should visit communities more often and interact directly with kids
- Milpa should talk with the kids when he visits
- Television advertising should occur more on Imparja TV rather than NITV, as the community does not watch NITV as frequently.

A child was present during the focus group with his mother. When asked by his mother if he could understand Milpa's message even though Milpa does not speak, the child indicated that he was able to.

#### Remote Jobs and Community Programme (RJCP) Group

The participants were five male community members. Key insights include:

- Recognition of Milpa was low among all participants
- One participant suggested 'Milpa' was the Warlpiri word for 'eye'
- After a picture of Milpa was shown, the men identified Milpa as a goanna, gecko or frog
- Eventually, two participants realised Milpa talks about clean eyes and hands.

Suggestions to improve the campaign included:

- More frequent visits to keep the message strong
- Football players such as the Melbourne Demons should also visit the community more often to keep the message strong
- Check-up days with the clinic attending the school and homes
- Hip-hop road shows and BBQs
- The school should also check and encourage clean hands and faces.

There was also a strong theme of 'leading by example', with parents and the community in general setting a standard and encouraging the children to follow.

Another interesting insight was that children see Milpa at school, and then take the message home to their parents.

## Finke

#### Shire Office Group

The participants were five elderly women and one young woman. Key insights include:

- Milpa was recognised and his message understood by all of the group members
- The women had seen Milpa on a variety of communication mediums, including television and posters, had received education at the clinic and had seen Milpa at the school
- The women considered dust from dirt as the main cause of trachoma, and felt that smoke from fires can cause trachoma
- Milpa and the message of trachoma is well recognised by children throughout the community
- The children in community get excited for Milpa to visit the school
- The women remembered a time when Milpa and Yamba the Honey Ant both visited the school. The women expressed a need for the mascots to also visit other parts of community to ensure the message is spread to everyone
- The group concluded that parents, carers and teachers at the school should be responsible and encourage clean faces and hands.

The women suggested promotion ideas including:

- Community events (such as concerts) at the Finke Desert Race with Milpa and the Melbourne Demons players
- More posters in community
- Milpa doing activities in places outside of school, such as bush trips where children can be shown how to keep their eyes clean without running water (carrying water and face washers).

#### **Community Group**

The participants were five women. Key insights included:

- Milpa being recognised in the context of an animal; his physical appearance is 'good for kids to look at and as bush tucker'
- Milpa is associated with a message of trachoma
- Song and dance encouraged the children to participate and were perceived positively
- The women associated Milpa with the message of 'clean faces, strong eyes'
- The women associated Milpa with getting eye drops
- Milpa coming into community to share the message was important.

#### Ntaria

#### **Community Group**

The participants included seven women, all of whom were grandmothers except one. Key insights include:

- Participants were not very familiar with Milpa; only two women had seen him on Imparja TV
- Although people came to community to distribute tablets for 'stronger eyes', the participant was unaware where they were from

- The participants discussed a time when a goanna visited the school, but they were not aware of the goanna's name
- The women spoke of poor eyesight and attributed this to trachoma
- Most people keep themselves and their children clean by showering every day
- School staff also ensure students are clean
- Milpa should attend community events more to increase awareness (concerts, discos, sports)
- Football is enjoyed across all age groups and genders in the community, and therefore the Melbourne Demons should come and promote the campaign
- Milpa should bring stickers to take home
- The community always has access to running water even when they go bush (waterholes).

#### **Rangers Group**

Participants included four females. Key insights include:

- Participants were all aware of Milpa and his association with the message of trachoma
- The women had seen Milpa from a variety of media including personal visits with footballers, television and posters
- Children were getting the message very well and taking notice
- The school has a key role in the promotion and cleans children's faces
- Some people in the community remain disengaged
- More work needs to be done with adults, including education on what trachoma really is.

#### **Red Sand Hill Outstation Group**

Participants included two males and four females. Key insights included:

- Milpa was recognised as bush tucker/meat
- The group understood that Milpa was associated with washing faces, and that eye drops are available at the clinic if they have sore eyes
- The group expressed that the promotion should be in language
- Milpa is understood well by the children, but not the adults
- The campaign could be improved by providing take-home materials such as stickers or posters for parents to encourage children to wash their faces.

## Lajamanu

#### **Childcare Centre**

The participants were five women and either staff at or parents of children who attend the childcare centre. Key insights include:

- The women were interested in determining if Milpa was a gecko or a lizard. After much discussion they concluded he was a gecko
- Awareness of Milpa was low, except one woman who said 'clean eyes'.
- The women said that 'Milpa' is the Warlpiri word for 'eyes'

- Following an introduction of Milpa's message by the research team, the women expressed a need for Milpa to have more of a presence around community (e.g. at childcare)
- Song, dance and puppets are effective for communicating with children
- The women were interested in collaborating with Milpa on a song with actions for the children.

#### **Early Learning Centre**

The participants were the members of the Stronger Communities for Children Board. Key insights include:

- The group described Milpa to be a gecko or lizard and also as the Warlpiri word for 'eyes'
- The group were aware that Milpa was the trachoma ambassador
- Football players were commonly cited for their role in the campaign
- There is community awareness associated with the campaign; however, it is considered as a message for children due to the way it is marketed
- Targeting adults in the campaign would be beneficial
- Barriers to cleaning faces included lack of supplies (soap), housing maintenance, isolation, poor quality bathrooms, and sinks in houses being too high for children.

#### Warburton

Participants were two males and ten females. Key insights include:

- Milpa is well known throughout the community due to a video the children were involved in (that is also being used at other communities) and the mural on the local store
- The message of Milpa was understood as keeping faces and eyes clean and the need to wash the eyes thoroughly everyday
- The group indicated no reasons for not keeping faces clean
- The group said that it is 'good' when Milpa comes into community.

The group had no suggestions for improving the campaign because it was working well already.

#### Pukatja

It was hard to get people together to take part in a focus group due to a cultural ceremony that was still ongoing in community at the time. The Ninti One team managed to talk to individuals and small groups of pairs and up to one group of four women, two young ladies and two elderly ladies.

When a picture of Milpa was shown to people, there was an initial reaction that Milpa was familiar and they may have seen him somewhere before. However, the message that Milpa is relaying was not known among the majority of people. Overall, very few people knew about Milpa. People tended to know more about trachoma from personal experiences within their family rather than the campaign.

Trachoma awareness also comes from other positions in the community, including childcare workers and clinic staff. The goanna is part of the dreaming for some people in the area, which gives it a different meaning.

Residents who were interviewed suggested that Milpa will need to make more of an appearance around the community and deliver the message more broadly as children need to hear this more often as well. One lady spoke about her son having trachoma and how sad it makes her feel. Another said that children learn mostly from mothers and some fathers.

It seems that the message is not reaching people at Pukatja. No posters were sighted in the clinic and other public places, as they were in other communities.

People also started to refer to Milpa as 'Kuru', which is the Pitjantjatjara word for eyes. They also stated that maybe they localise this word for the Anangu Pitjantjatjara Yankunytjatjara Lands area so people understand better.

A second visit took place in early April by two female Aboriginal Community Researchers and one male Aboriginal Community Researcher. They all had a family connection to Pukatja and were speakers of Pitjantjatjara language. Although it was difficult to bring together a focus group during this visit, the researchers managed to talk to several small groups of men and women and gather information about what they knew about Milpa.

In summary, taking into account both visits, it seems that not a lot of people know about Milpa and only a few could say that they have heard about him from visiting other communities. They feel that Milpa needs to talk to more people at Pukatja and that there needs to be more awareness around the community. A lot of people also suggested that Milpa's name could be changed to the Pitjantjatjara word Kuru, which means eyes.