

Childhood Anaemia Knowledge and Resource Development Project Report

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EXECUTIVE SUMMARY

Childhood anaemia is a growing concern in the NT as 22% of Aboriginal children aged 0-4yrs are reported to be anaemic. Low birth weight, preterm infants and infants born to mothers who are anaemic during pregnancy have reduced iron stores at birth that are rapidly depleted in the first few months of life. Anaemia is associated with adverse effects on physical and cognitive development in the early years and reducing potential for educational attainment and employment in later years.

Iron deficiency anaemia from an inadequate diet is the most common type of anaemia, however there have been no published studies that document the dietary intake of young Aboriginal and Torres Strait Islander children. Of particular concern is the emerging evidence from the ABCD National Partnership project that suggests guideline-specified screening, treatment, follow-up and brief interventions are poorly implemented; the reasons for which are unknown.

Our Knowledge and Resource Development project was a pilot to establish if photographing or video recording a child's dietary intake was acceptable in a remote community setting. We also wanted to explore the anaemia health literacy of health practitioners and community members and gain an understanding of the factors influencing the low implementation of anaemia screening and treatment guidelines.

We were able to establish that the use of photographs or video recordings was an acceptable tool to provide evidence on the dietary intake of children. Families did not find this tool culturally unacceptable, however cultural obligations often prevented them from taking photographs or video recordings of dietary intake. Through group and individual interviews we were able to establish that there was broad community knowledge of anaemia that was more specialized for health practitioners. Community members and health practitioners had a good understanding of what foods prevent and treat anaemia however further exploration of their knowledge is required to identify barriers that prevent people from eating iron rich foods.

Knowledge of common causes and medical treatments for anaemia were known, however this knowledge was often limited to the personal experience of the community member or the speciality area of the health practitioner. Improvements in health practitioner knowledge and processes for follow-up care with adaptations to

the electronic health record system are recommended to improve the implementation of the anaemia screening and treatment guidelines.

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LIST OF ABBREVIATIONS

- ACW – Aboriginal Community Worker
AHW – Aboriginal Health Worker
ASQ – Ages and Stages Questionnaire
BIITE – Batchelor Institute Indigenous Tertiary Education
CII_CHR – Certificate II in Child Health Research
CDEP – Community Development Employment Program
CRCAH – Cooperative Research Centre for Aboriginal Health
FW – Felicity Ward (Project Manager)
GG – George Gurruwiwi (Aboriginal Community Worker)
IDA – iron deficiency anaemia
JDG – Janice Djilliri Garrawirrtja (Aboriginal Health Worker)
LBD – Leanne Bundhala Dhurrkay (Aboriginal Health Worker)
LM – Lorraine Martin (Indigenous Strategy and Development Coordinator)
LQ – Linda Quall (Project Officer Indigenous Programmes)
Menzies – Menzies School of Health Research
MOU – Memorandum of understanding
NT – Northern Territory
RGD – Roslyn Gundjirryirr Dhurrkay (Senior Aboriginal Community Worker)
RAN – Remote Area Nurse
SL – Selma Liberato (Dietician and Public Health Nutritionist)
SP – Stephanie Puska (ABCD National Partnership Project - Research Officer)
TK – Thérèse Kearns (Epidemiologist)
VG – Veronica Gondarra (Aboriginal Community Worker)

BACKGROUND

Childhood anaemia is a growing concern in the NT as 22% of Aboriginal children aged 0-4yrs are reported to be anaemic.[1] Anaemia is associated with adverse effects on physical and cognitive development in the early years and reducing potential for educational attainment and employment in later years.[2-4] The most common type of anaemia worldwide is iron deficiency anaemia (IDA) from nutritional deficiencies, that are often complicated by or coexist with parasitic infections and recurrent infectious diseases.[3, 5]

Parasitic infections with hookworm, the most common parasite causing anaemia, have reduced significantly in Aboriginal communities in the NT since the de-worming program began almost 15 years ago.[3] Whilst the treatment regime has been effective for hookworm it only reduces the intensity of infection for the whipworm, *Trichuris trichiura*, that is now the most common parasitic infection detected in faecal samples.[6, 7] Reducing the intensity of the whipworm infection is beneficial as previous studies have found that a high intensity of *T. trichiura* infection is a significant risk factor for anaemia.[8, 9]

Low birth weight, preterm infants and infants born to mothers who are anaemic during pregnancy have reduced iron stores at birth that are rapidly depleted in the first few months of life.[4] In the NT, 14% of children are born with a low birth weight (<2,500 grams) and 15% of mothers are anaemic during pregnancy.[10] Evidence from the ABCD National Partnership Project suggests that guideline-specified screening, treatment, follow-up and brief interventions to identify those at-risk individuals are poorly implemented; the reasons for which are unknown.[11]

It is believed that the majority of IDA is nutritional however there have been no published studies that record the daily dietary intake of young Aboriginal and Torres Strait Islander children that are anaemic compared to those that are not. Improving our understanding of infant and child dietary habits and its effect on cognitive development is essential to identify underlying causes or gaps in knowledge for the development of appropriate and culturally acceptable prevention and management strategies.

Our aim was to develop knowledge of and resources for the dietary intake of children and to establish if focus groups and individual interviews were an appropriate method

to explore the anaemia health literacy of health practitioners and community members.

1 AIMS

- To pilot a dietary intake tool to record the daily intake of food and beverages for children.
- To explore the childhood anaemia health literacy of health practitioners and community members.
- To gain an understanding of the factors influencing the low implementation of childhood anaemia screening and treatment guidelines.

1.1 Research Questions

1. Was video recording of meal preparation and eating, including breast feeding and drinks consumed, an acceptable dietary tool to use in communities?
2. Were focus groups an acceptable method to obtain information on anaemia health literacy and the low uptake of anaemia screening and treatment guidelines or will individual in-depth semi-structured interviews be a more appropriate method, or do we need both methods?

2 METHODS

2.1 Funding, Ethics and Collaborations

The funding agreement with the Lowitja Institute was executed on 17/12/2013. Conditional ethics approval was given on 14 December 2012 with full approval obtained on 27 March 2013, from the Human Research Ethics Committee of the Northern Territory Department of Health and Menzies School of Health Research (HREC 2012-1898).

This project was implemented in collaboration with Selma Liberato's (SL) project that was funded by Menzies Small Grant Scheme, 'Building capacity to evaluate and monitor dietary intake at remote communities" (HREC-2012-1904). SL was the principal investigator for her project and the second investigator for this project.

SL's aims were complimentary to ours and included:

- design a dietary intake methodology and accompanying training method

- build the capacity of community-based Indigenous people to collect dietary intake data.
- provide insights on the acceptability and feasibility of using a dietary intake tool for Indigenous people in a remote community setting.
- empower Indigenous people to better understand nutrition and nutritional content of foods, with the ultimate aim to improve the health of people in remote Aboriginal communities.

As both projects were inter-related and implemented simultaneously relevant aspects of SL's project were incorporated into this report.

2.2 Study initiation

A two day study initiation meeting in March 2013 was attended by:

- Therese Kearns (TK)
- Felicity Ward (FW)
- Leanne Bundhala Dhurrkay (LBD)
- Roslyn Gundjirryirr Dhurrkay (RGD)
- George Gurrwiwi (GG)

The initiation meeting included:

- Mandatory report training by Niki Patmios, from the Office of Children and Families, Northern Territory Government
- Focus group training delivered by Bonita Moss (Educational Psychologist/ Research Officer from The Centre for Child Development and Education at Menzies),
- iPod Touch device training for video/photographing delivered by Sarah Mares (Child and Family Psychiatrist from The Centre for Child Development and Education at Menzies)
- Project content delivered by TK and FW (Appendix 1 – Training Timetable).



Study initiation meeting in Darwin, March 2013.

2.3 Training program

The nationally accredited training program, Certificate II in Child Health Research (CII_CHR) was developed in 2009 with funding from the Cooperative Research Centre for Aboriginal Health (CRCAH). The training program was put on scope by the Northern Territory Health Department's Registered Training Organization with a MOU for Menzies to deliver the training. The CII_CHR comprises of four units of competency:

1. BSBWOR202A – Organise and complete daily work activities
2. CHCPROM401C – Share health information
3. HLTAHW301B – Work in Aboriginal and/or Torres Strait Islander Primary Health Care context
4. HLTPOP306C – Establish agent of disease transmission and mode of control

The training program was developed so that it could be adapted to different research projects using the project specific research materials to train the learners in the research subject matter related to the project. The CII_CHR was adapted for the anaemia project in February and March 2013 and delivered in April 2013 by Menzies staff: TK, FW, RD, LBD, GG SP, SL, LQ and LM. The delivery of the CII_CHR was funded by SL Menzies small grant. Guest speakers were invited from Yalu marnggithinyaraw to assist in the delivery of two units:

- HLTAHW301B Work in Aboriginal and/or Torres Strait Islander Primary Health Care context.
- CHCPROM401C Share Health Information.

Incorporated into the 'Organise and complete daily work activities' unit was training in using household measurements and how to take pictures of foods using cameras. Use of cooking utensils such as common mugs sold in store were used so that participants became aware of the volume capacity of the mugs compared to standard household measurements.



Examples of measures used to determine quantity and type of food and drinks consumed.

Four graduates from previous years (LBD, RGD, GG and JDG), co-facilitated many of the presentations, conducted language translation and assisted in determining competency, particularly in Share health Information and Work in Aboriginal and/or Torres Strait Islander Primary Health Care context (*Appendix 2 – Timetable for the delivery of CII_CHR and Nutrition unit*).

An additional unit of competency was delivered by Selma Liberator (SL) – ‘HLTAHW407B Provide nutrition guidance for specific health care,’ to provide the nutritional information required for the projects. A MOU was signed with Batchelor Institute of Indigenous Tertiary Education (BIITE) to deliver this unit.

2.4 Recruitment to training program

Community members in the remote community were recruited to the training program by FW, RGD, LBD and GG after consultations with:

- Health services – one remote homelands health service and one local community health service
- Employment agencies - Community Development Employment Program- (CDEP) and a local employment service
- Individual community members

Trainees were informed that the CII_CHR included the collection of a four day food diary and if informed consent was obtained that we would use the information collected for our Knowledge and Resource Development Project and SL's project. Trainees participating in the research component of the training were compensated for their time.

2.5 Collection of dietary intake

During the CII_CHR, trainees were instructed on the use of a camera and/or iPod Touch to collect recordings of the food and drinks consumed by the child over 4-7 days. Dietary data collected from the photographs and/or videos for which informed consent was obtained was used for both Knowledge and Resource Development and SL's research projects (*Appendix 3 – Child and Parent/Guardian Consent Form*). The family was informed that a thank-you food basket would be provided (SL funding) for participating in the collection of the child's dietary intake.

The researchers visited the consenting families on a daily basis to view and download the photographs/video recordings onto a laptop computer. The Dietary Recall form was completed each day by asking the parent/caregiver what the child had eaten the day before and viewing the photographic/video footage. (*Appendix 4 – 24hr Dietary Recall form*). The information collected on the Dietary Recall form was used to enter the data into the Foodworks database.

2.6 Community member focus groups and individual interviews

During the study initiation meeting prior to the commencement of the project, the researcher team discussed and generated a list of questions that could be asked of community members to determine anaemia health literacy. The questions were then translated into the local language (Djambarrpuyngu- a language of ¹Yolŋu Matha) by RG, GG and LBD. Families of the children that had participated in the photographing/videoing of dietary intake were asked for consent to participate in a family focus group after completion of the child's 4-7 day dietary intake.

Consent was obtained to record (video/audio) the focus groups and interviews so they could be translated from local language into English for analysis (*Appendix 5- Focus Group Consent Form*). The questions were asked in local language by LBD, RG and GG and videoed by FW. The video was then viewed by the research team,

¹ Yolŋu Matha is a cover term for the languages of the Yolŋu (Yolŋu), the Indigenous people of northeast Arnhem Land in northern Australia.

translated and a written transcript in English was produced by LBD and RG. FW collated all the responses into two documents, 1) Response by question and 2) Response by interview number. FW and TK measured the knowledge of responses using a scoring matrix that was developed using information from the anaemia fact sheets from Kidney Health Australia, Raising Children Network and the Remote Health ATLAS.[12-14]



Roslyn and Bundhala translating.



Family Focus Group.

2.7 Health Practitioner focus groups/individual interviews

Permission was provided by the health service managers to approach staff for participation in either a focus group or individual interview on childhood anaemia. Consent was obtained to video/audio tape the responses so written transcripts could be used to analyse the responses (Appendix 6- Health Service Consent Form).

TK and LBD developed questions to ask the health practitioners in English that were translated into local language by LDB and RG. The questions were modified after the first three interviews to enrich the content of the responses. LBD was the interviewer for the majority of the focus groups or individual interviews with TK and RD recording. LBD reviewed all the video and audio recordings and provided written translation from local language to English for the analysis. FW collated all the responses into a 'Response by question' document.

2.8 Data Analysis

Food diary analysis was conducted by SL and TK. Each participant provided video/photographic images that were supported with a daily written recall of foods consumed. This data was entered into the FoodWorks nutrition software by SL to produce a FoodWorks report on daily nutritional intake (Appendix 7 – Foodworks Report). Each parent/guardian of the participant was provided with a summary of the

participant's nutritional intake and some brief advice on how to improve intake if required.

Anaemia health literacy knowledge for the family and community interviews was analysed by TK and FW. The 'Response by interview number' document was reviewed individually by TK and FW who categorized the level of knowledge as: 1=Poor, 2=Fair, 3 Good, 4=Very Good, 5=Excellent using the scoring matrix. The results were summarized to determine the overall anaemia knowledge of each group.

TK, FW, and BM coded the 'Response by question' document for the family and community member interviews to provide a summary of the responses. TK reviewed the knowledge of the responses provided by the health practitioners using the CARPA Standard Treatment Manual and the CARPA Reference Manual as a reference point for knowledge.[3, 15]

2.9 Research translation plan

The research translation was delivered in the remote community during the week 9-13 December 2013 (Figure 1). Both health services and aged care were visited during the week as well as the Community Advisory Board bi-monthly meeting. All participants that were enrolled in the project were visited to discuss the findings.

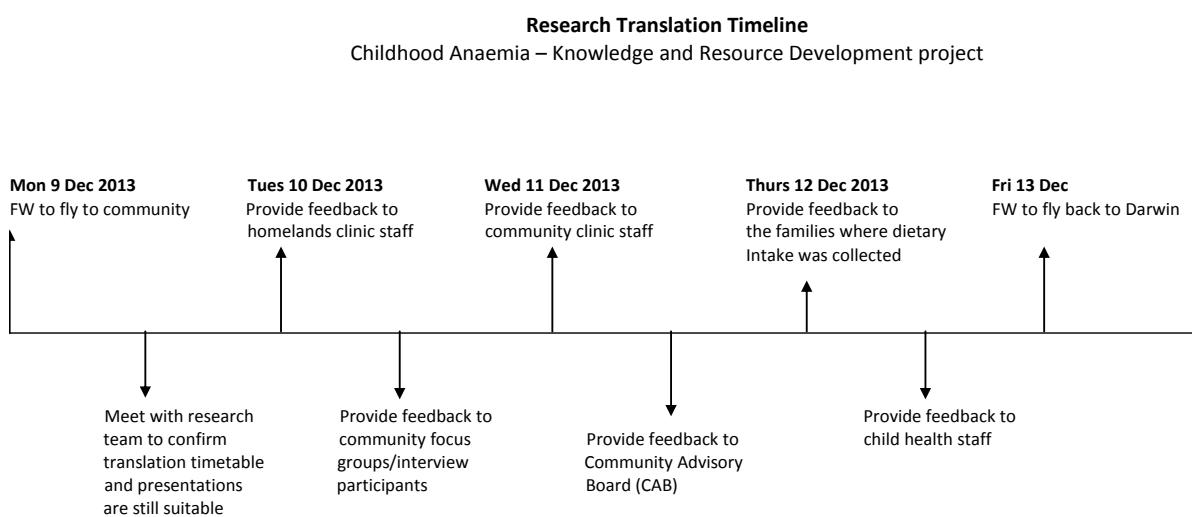


Figure 1. Research Translation Plan.

3 RESULTS

3.1 Training Program

Twelve learners enrolled in CII_CHR training program. Ten completed four units of competency, one completed two units and one completed one unit. The learners were from the remote homeland health service (2 family workers - 1 male and 1 female), Community Enterprises Australia (3 females and 1 male), and six were Centrelink recipients.

A total of twenty-eight participants attended the HLTAHW407B_Provide nutrition guidance for specific health care delivered by SL (Table 3.1). This was a new unit for AHW training as part of the HLT43907 – Certificate IV in Aboriginal and/or Torres Strait Islander Primary Health Care Practice. All current registered AHWs had to update their qualifications to include this unit and were invited to attend.

Table 3.1. Attendance at HLTAHW407B_Provide nutrition guidance for specific health care.

Community Health Service	11 AHWs, 1 driver 1 Social Worker
Remote Homelands Health Service	2 AHWs, 1 Family Worker
Community Enterprises Australia	3 CDEP employees
Menzies School of Health Research	3 ACWs, 1 Project Manager 1 Epidemiologist
Centrelink recipients	4 community members



Learners attending the nutrition unit delivered by Selma Liberato, April 2013.

3.2 Collection of dietary intake

There were eight food diaries collected on children aged 11 months to eight years (Table 3.2). From the 12 learners enrolled in the CII_CHR, all consented to collect dietary intake information on a child in their home or a relative's child. Of the 12 learners, six collected dietary information on five children over a range of 1-4 days. One learner collected photos and/or videos for four days, four collected photos and/or videos for two days (two learners that were sisters collected information on one child) and one learner collected photos and/or videos for one day. The three other food diaries were collected by two of the local facilitators for the CII_CHR training (JDG and RD) and one by a previous graduate of the CII_CHR who was on maternity leave, Veronica Gondarra (VG). These diaries were collected for two days by two graduates and one day by one graduate.

Table 3.2. Summary of dietary intake.

Cert II_CHR	Age of child	No. of completed days of dietary recall for foodworks report	No. of days photos/videos were taken	No. of meals captured by photo/video (%)
Learner	11 months	4	2	4 (67)
Graduate	21 months	4	2	2 (33)
Learner	22 months	1	2	2 (33)
Graduate	31 months	4	1	2 (67)
Learner	35 months	4	4	10 (83)
Learner	4yrs	1	1	1 (33)
Graduate	6yrs	1	2	4 (67)
Learners x 2	8yrs	4	2	4 (67)

The food and drinks consumed by the children were recorded by two people on a Menzies iPod Touch, two used a disposable digital camera (SL project equipment), two used their own personal equipment, a Samsung mobile phone and a personal iPod Touch, and the remaining two used donated cameras (cannon). Of the meals that were recorded during the 1-4 day data collection period, breakfast was the most photographed/videoed meal being recorded 13 times. Lunch was the second most captured meal recorded 10 times, with dinner being the least recorded meal with only six video/photographic recordings. Snacks provided in between main meals were recorded seven times and were generally from young children (4 were aged<3yrs and 1 was 4yrs old) or from two children who were still being breast feed.

From the Foodworks reports generated, only one of the eight children was getting an adequate iron and energy intake (Table 3.3). Two other children had an adequate energy intake, however they were lacking essential vitamins needed for optimal growth and development. Five of the eight children did not have an adequate amount of food each day to grow well, however two were breast feeding which was not included in the Foodworks reports.

Table 3.3. Percentage of recommended iron and energy from the dietary intake.

Age	Percentile (Weight for age)	Iron %	Energy %	Adequate daily amount of food to grow well
11 months (BF)	< 85 th	27	48	No
21 months (BF)	< 85 th	80	112	Yes
22 months	< 50 th	62	122	Yes
31 months (BF)	< 15 th	84	74	No
35 months	< 50 th	131	107	Yes
4yrs	< 15 th	90	79	No
6yrs	< 15 th	83	52	No
8yrs	< 15 th	81	74	No

*BF - Breastfeeding

There were six learners who did not collect food diaries on a child during the study period and the reasons included:

1. involved in his son's men's business ceremony.
2. unwell with asthma and then part of the mourning ceremony of an unexpected death.

3. living in a tent at a house where a funeral was occurring and was unable to take photos/videos.
4. completed two units from the CII_CHR and did not attend all the training.
5. completed one unit in the CII_CHR and went back to Darwin.
6. had work commitments and could not participate in the data collection.

3.3 Community member focus groups and individual interviews

Six family interviews were conducted with eight of the families who had collected dietary intake on a child in their home (Table 3.4). Another four interviews were conducted with members of the community that often included a relative of the child that had been enrolled in the study. A total of 39 people participated in the discussions (*Appendix 8 – Question Guide for Community Member Focus Groups*).

Table 3.4. Details of community member focus groups and individual interviews.

Group	Type of Interview	No. in Group	Male	Female	Participation in discussion
1	Family group	6	0	6	3
2	Individual family member	1	0	1	1
3	Family group	2	0	2	2
4	Family group	6	0	6	4
5	Family group	5	2	3	4
6	Individual family member	1	0	1	1
7	Community group	2	1	1	1
8	*Mixed group	4	0	4	4
9	*Mixed group	10	3	7	6
10	Community group	2	1	1	2
Total		39	7	32	28

*Mixed is a combination of community and family members

There was a mix of anaemia knowledge in the community with the majority of interviews having good to very good anaemia knowledge (Figure 2). The individual interview with one participant who had ‘very good knowledge’ was a staff member at the local clinic and had been anaemic in the past.

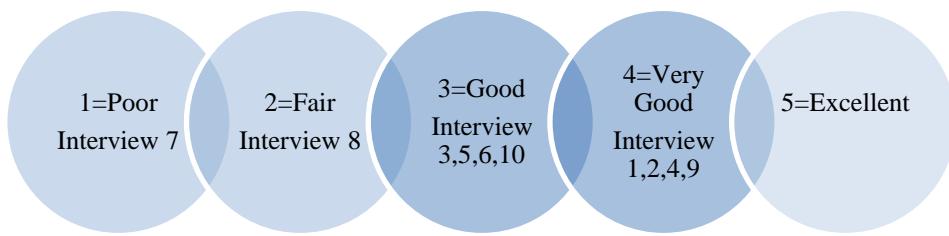


Figure 2. Anaemia Knowledge

3.3.1 Summary of responses from community member focus groups and individual interviews.

Q1. What is anaemia? Weak blood?

Respondents referred to the term anaemia as ‘weak blood’, ‘low blood’ or ‘no blood’. Interviewees understanding of the causes of anaemia were embedded in their responses to “what is anaemia”. These responses included ‘worms’, ‘lack of good food’, ‘drinking black tea’, ‘walking in the rain with bare feet’ and ‘no iron in the body.’

Knowledge – Good understanding.

Recommendation – Change question to ‘What does anaemia mean to you?’

Q2. Why do you think people have weak blood?

There was comprehensive discussion about the reason why people have weak blood. This question was answered well with the most common responses being, ‘not eating enough fruit, not eating red meat, lack of vitamins, eating too much take away food and walking bare foot.’ One group mentioned the past traditional way of life verses the present, ‘olden days people use to live healthy and use healthy food from the bush and seafood, and it really helped our people with their health and their bloods.’ There was some discussion around the health of mothers and their unborn child, ‘mum wasn’t eating good healthy food maybe sniffing petrol, smoking cigarette or alcohol’. There was also a comment made about the effect of anaemia on development, ‘because why people and kids slow learning and slow growing.’

Knowledge – Very good level of understanding.

Recommendation – Use this question in future projects.

Q3. What happens to people if they have weak blood?

This question generated many responses that included, 'feel weak, feeling tired, no strength, no energy, weight gets low, underweight, sleepy, floppy, crying, ulcer, thrush, sore mouth, not eating much food, that worm gets in, don't feel like eating, get skinny, feel dizzy, sunken eyes, light/pale skin, no fluid in body, headache. There was no mention of slow learning or the effects on brain development however one responder did bring this up in the previous question.

Knowledge – Limited understanding of long term implications of anaemia on daily living.

Recommendation – Improve community knowledge of long term implications of anaemia particularly the impact on physical growth and cognitive development for children. Suggested forums: parenting groups, child health checks, information sessions by community health workers or health promotion staff.

Q4. How do they fix it?

This question was well answered and included nutrition and medication responses. Responses related to nutrition included: 'seafood, turtle, shells, mussels, half cooked meat, kangaroo meat, just the raw or half cooked that's what our people use to have their bloods strong; don't give kids tea, that means kids get weak; bush fruits and shop fruits, billy goat plum, wild plum, red green plums which have vitamins in them.' There were two responses that included water could 'fix' anaemia.

Responses related to medications included: 'sometimes they give the kids medicine - worming medicine; sometimes they take blood at the clinic so they will give the night medicine, sometimes they get injection; sometimes they give them iron medicine, iron tablets or medicine from the clinic.'

Knowledge – Very good level of understanding.

Recommendation – Further explore the idea that eating half cooked meat could fix anaemia. Where did this information come from? Is it a belief that the blood seen in half cooked meat is what fixes anaemia? Is it from the knowledge that the bloodier the meat the more iron it has? Frequency of iron foods was not discussed and needs to explored further.

Q5. How do you prevent it?

The responses focused on the importance of eating good food and other environmental factors such as keeping your house clean. Responses included, “eating half cooked meat, iron, and good food, don’t give black tea to kids, keep the house clean every day, bush foods, iron foods and fruits and vegetables”..

Knowledge – Good level of understanding.

Recommendation – Additional questions: 1) How often should these good foods be eaten? 2) Are the good foods readily available? 3) What makes it hard to eat good foods?

Q6. How do you know if you've got weak blood?

This question was answered well. e.g., ‘tired, weak, sleepy, no strength and dizzy.’

Knowledge – Very good level of understanding.

Recommendation – Remove question as similar to that asked in question 3.

Q7. How do they treat it? Medicine?

Responses included a range of knowledge about specific medication, ‘crushed up medicine tablet’, ‘that same medicine’, ‘medicine called albendazole’, ‘medicine’ and ‘iron injections and tablets’. The majority of the groups identified the treatment as iron injections or tablets and elaborated to suggest the need for bush foods to help treat anaemia.

Knowledge – Good level of understanding.

Recommendation – Remove question as similar to that asked in question 4.

Q8. Have you or any of your children had this problem?

This question was a great way for parents to share their experiences with anaemia. Three respondents had in depth discussion with the research team about their experience with anaemia.

Knowledge – Good knowledge of anaemia for those that have had personal experience.

Recommendation – Use this question to explore people's knowledge further about anaemia and their experience with it.

Q9. What treatment would you prefer for yourself and what would you choose for your child?

During the research translation week in December 2014 we asked community members what anaemia treatment they would prefer for themselves and what treatment they would choose for their children (Table 3.5). The majority of adults preferred to take iron tablets for three months but chose iron injections for their children. Some of the response included: 'tablets make tummy upset, easy to have injection, kids don't like the liquid to drink, children don't like the taste, kids don't like injection but we force, would be better if you could hide it in food.'

Table 3.5 Community member responses to anaemia treatment

<i>Treatment option</i>	<i>Yourself (%)</i>	<i>Your child (%)</i>
No treatment	0	0
Iron Injection	3 (19)	9 (60)
Iron Tablets	13 (81)	1 (7)
Liquid	0	5 (33)

3.4 Health Practitioner focus groups/individual interviews

Individual and group interviews were conducted with health practitioners in July and August 2013 (Table 3.6). Twelve health practitioners consented to be interviewed of which there were three RANs, eight AHWs and one ACW. There was only one General Practitioner in the community when we were conducting the interviews who declined to be interviewed. The style of interview conducted was different between the two health services ie. health service 1 preferred to be interviewed individually whereas health service 2 preferred to be interviewed in groups.

Table 3.6. Details of health practitioners interviewed

Interview	Location	Questionnaire 1	Questionnaire 2
1	Health service 1	1 x AHW	
2	Health service 1	1 x RAN	
3	Health service 1	1 x AHW	
4	Health service 1	1 x AHW (trainee)	
5	Health service 1		1 x RAN
6	Health service 2		1 x RAN, 1x ACW, 1x AHW (not currently registered)
7	Health service 2		4 x AWH

3.4.1 Summary of responses from health practitioner interviews

Q1. What is anaemia?

Most of the AHWs described anaemia as low blood, weak blood or no blood whereas the RANs responses described anaemia as “low haemoglobin”. No health practitioners provided a response that made reference to a diagnostic range for children or adults.

Knowledge – Adequate, responses may improve with different questions.

Recommendation – Change question to, “How do you explain to people what anaemia is?” “How do you know as a health practitioner that someone has anaemia and needs treatment?” “What would you do if the Hb was just below the threshold for not needing treatment?

Q2. What happens to people if they have anaemia?

All the health practitioners described the symptoms of anaemia as, ‘tired, weak, no energy, and dizzy,’ however only the RANs made comments on growth that included: ‘not growing well, so they are smaller than what we expect’, ‘they don’t carry oxygen in their blood as well as someone who doesn’t have anaemia’, ‘lots of infections and not able to get rid of infections easily’ and ‘not grow and develop as they normally would’. There was no discussion about how anaemia affects children’s cognitive development and learning at school or how anaemia may impact on a person’s daily living activities and ability to work.

Knowledge – Acute symptoms were well known what was not included in the responses were:

- 1) Long term effects of anaemia on the cognitive development of children and how this affects their learning ability at school.
- 2) Impact of anaemia on daily living.

Recommendation

- 1) Health services have a child health expert employed to work with children.
- 2) Improve knowledge of anaemia through the development of an anaemia learning module for remote health practitioners that includes how to use the electronic health record system. This module should be completed within 3 months of first rural or remote placement (Appendix 9 – Anaemia education module for health practitioners).

Q3. Who gets anaemia?

Responses were very broad and included, “adults, kids and everyone.’ Practitioners specializing in child health were the only ones to talk about pregnant women, preterm and low birth weight babies. One RAN mentioned ‘blood loss through trauma,’ ‘people with other conditions like cancer.’ No one discussed people with chronic kidney disease.

Knowledge – Generalist practitioners had limited knowledge on childhood risk factors for anaemia (i.e. low birth weight, preterm) or what conditions in adults may predispose them to anaemia (i.e. pregnant women, chronic kidney disease).

Recommendation

- 1) Anaemia education module.
- 2) Improve electronic health record prompts to include a treatment plan for children when a low birth weight or preterm gestational age at birth is entered.

Q4. What causes anaemia?

When discussing the causes of anaemia, most answers were focused around not eating the correct foods. One RAN talked about trauma and blood loss. One group focused on social aspects that included gambling and not enough money to buy food. Infections were associated with anaemia but were not described as a cause of anaemia. There was no mention of worms or other conditions at this question, e.g. kidney disease, cancer.

Knowledge – Good knowledge around nutritional and social factors associated with anaemia what was not mentioned in the responses was a comprehensive understanding of what conditions/infections predispose individuals to anaemia.

Recommendation

- 1) Anaemia education module.
- 2) Discuss with midwives how they complete the 6 week check and document this in the electronic health record.
- 3) Discuss with health practitioners what they do if the midwives have not completed the 6 week check.

Q5. How do we check if someone has anaemia?

Venous and capillary blood was the most common answer to this question. The question was changed after the first three interviews to, “when do you check if people have anaemia?” This stimulated responses such as ‘every two weeks (trainee AHW)’, ‘three monthly check ups’, ‘if presenting with symptoms’ and ‘if sick we check, otherwise when health check is due’.

Knowledge – High

Recommendation – Change question to “How do you know when to check if people have anaemia?”

Q6. What do you tell anaemic people about treatment?

The information that health practitioners gave about anaemia treatment to people attending the health centre included oral and injectable iron as well as education on nutrition. Responses about nutrition education included, ‘we give them education,’ ‘the first thing I talk about with them is what type of foods they are eating and I try to explain what foods will help bring up your haemoglobin.’

No one talked about side effects of treatment or the taste of the oral liquid or the length of time the treatment is required for, or, that de-worming is recommended as well as iron replacement.

Knowledge – Good knowledge of treatment options and the need to discuss nutrition. What was not mentioned in the responses was discussion about the cause of the

individuals anaemia, side effects of treatment being administered and length of treatment ie. 3 months of oral treatment, 2-3 injections over one week.

Recommendation – Anaemia education module.

Q7. What treatment do you offer them?

Health practitioners in general had no preference about what iron treatment was offered. All practitioners stated that they gave the individual or parent the option and administered whichever drug was chosen. Responses included, ‘we give injection to children or medicine if the child’s not happy for us to give injection,’ ‘we might give oral iron or injections, depends on the family and what is going to be easy for them,’ ‘some people don’t like the tablet because it makes the colour of the gula (poo) change, go black in colour, make them feel yaka mynmak (no good) scared, they prefer to have needle instead.’ One RAN discussed folic acid, and said that she administered medication according to the CARPA manual. Deworming was only mentioned by one RAN and one AHW. The AHWs highlighted the need for the parents to be responsible in assisting the clinic to administer the medicine.

Knowledge – Good knowledge of what treatments are available, however only one practitioner made reference to giving what was recommended in CARPA as the treatment options differ depending on the haemoglobin result. The majority of practitioners did not mention deworming as part of the treatment regimen.

Recommendation

- 1) Anaemia education module.
- 2) Additional questions – ‘How do you know when people are suppose to return for treatment?’ ‘What do you do if people don’t return for treatment?’

Q8. Do you talk about food/diet?

All respondents stated that they discussed nutrition. The AHWs went into more detail about what they said. Responses included, ‘for Yolgnu people we get food from the bush, sea like turtle, kangaroo, fish and goanna,’ ‘it tells that person with anaemia should have meat- that it is half cooked or vegetables and also there is a roots from the bush or grass that there is a medicine to keep them strong or gives strength.’

Knowledge – Good knowledge of foods.

Recommendation – Change the question to, ‘What food or dietary recommendations do you talk about and how often should they have these foods?’

Q9. Do people take the treatment?

The AHWs were hesitant with their responses and evaded the question answering with, ‘some we give medicine orally or tablets to take home after food or meal and sometimes we give injection for 3 days,’ ‘I don’t know, maybe they do,’ ‘if the patient don’t take the medicine they will get sick and feel pain.’ The RANs responses were more direct and included, ‘for adults most of them will take the iron tablets because they understand the message of strong blood,’ ‘yes, but the compliance isn’t as good as I’d like,’ ‘I think they just forget a lot of the time and just lack of understanding of how important it is.’ One group discussed in depth how difficult it can be for some parents who are struggling with other personal issues in their lives and how they take this into account when caring for the anaemic child. Responses from this group included: ‘it’s hard one for us here we work with mothers often who are struggling anyway, so raising kids is hard for them they are the ones that have big problems,’ ‘so we try the quietly, quietly, gently approach because they have probably had a hard time from a lot of different areas.’

Knowledge – Practitioners expressed their opinions on treatment uptake but there was no commonality in the responses.

Recommendation – Change question to, ‘What do you do if people don’t take their medication?’

Q10. How do you find out if the anaemia has gone away?

This question was asked in the first three interviews and triggered responses about recalls in Communicare. The question was adapted to, ‘When do you bring people back to find out if their anaemia is improving? Responses included, ‘it depends on their treatment’, ‘with oral iron we go one month and then we test again’, ‘both for children and adults it would be after three months’ and ‘if it is real low, very quickly, we monitor it each day and then we do three monthly checks’.

Knowledge – Responses improved when the question was modified and in most part was answered with time frames outlined in the CARPA manual.

Recommendation – Adapt the question to say, ‘When do you bring people back to find out if their anaemia is improving?’

Q11. When you give treatment for anaemia do you put a recall in for when they need to be followed up?

Most respondents knew that a recall was triggered when a low Hb result was entered but did not identify consistent processes. The majority of respondents mentioned that they created a manual recall and entered the time frame that they wished to review the individual in manually. Only one RAN was able to clearly describe how the recall system worked and the anaemia plans. The practitioner identified the complexity of the anaemia plans and the recall system and describes the whole process as ‘a bit of overkill’ and identifies that other staff and programs within the health system have encountered trouble with using the system effectively, ‘the kids clinic found anaemia (in Communicare) too overwhelming to deal with.’

Knowledge – All practitioner responses included a recall however only one mentioned the anaemia care plan. The care plan prompt appears when a low Hb is entered however you need to click on the care plan prompt to fill out the details. The care plan provides the practitioner with all the treatment and other information that should be provided at that visit.

Recommendation

- 1) Review the processes and steps in Communicare for recording a low Hb so the care plan is used more frequently
- 2) Develop standard operating procedures for entering commonly seen conditions so data entry processes are generic.
- 3) Change the question to, ‘How and when do you follow up someone that is anaemic who requires treatment?’

Q12. What would you do if a person had a Hb of 108?

During the research translation week in December 2013, 13 health practitioners were asked to complete a question on what they would do if a person with a Hb of 108 presented to the clinic. It was explained that this figure of 108 was just below the normal value of 110. Three responses were provided to choose from and more than one response could be circled (Table 3.7). The majority of health staff would not treat a person with a Hb of 108 but have them return in 2-4 weeks to re-check their Hb level.

Table 3.7. Responses to multi-choice question from 13 health practitioners.

Responses	No. of responses	
Tell them to come back in 2-4 weeks to have it re-checked	10	
Tell them about iron rich foods	8	
Treat them with iron medicine	3	
<i>Responders inserted - deworm</i>	3	
Do you think this person could be iron deficient?	Yes	No
	6	7

3.5 Research Translation

Research translation was delivered in the remote community from 9-13 December 2013. Households participating in the photographing or video recording of a child's dietary intake were visited as well as Yalu, Birrk Birrk Shop, Aged Care and the Community Advisory Board meeting. In total, 32 community members participated in the research translation. There was a sense of pride with some of the community members when the researchers spoke of the level of knowledge that the community had in relation to anaemia. Other community members were pleased to hear that there was a good knowledge of anaemia in the community and appreciated that the researchers were returning to talk about the results of the project with them in local language. There was a lot of discussion about how to increase the consumption of iron rich foods which included educating young mothers and high school children, having theme weeks in the supermarket highlighting the iron rich foods and trips organized by council or CDEP to take people out hunting and fishing. Thirteen health practitioners participated in the research translation. Most of the discussion generated was directed towards the children's dietary intake and the adverse effects to cognitive development and learning.



George and Roslyn translating research findings to community members, December 2013.



TK translating research findings to health staff, December 2013.

4 DISCUSSION

Dietary iron deficiency and recurrent viral or bacterial infections are considered to be the most likely causes of anaemia in NT Aboriginal children.[3] Due to the paucity of community based studies on nutritional intake of young children and the belief that Aboriginal people are reluctant to be photographed or videoed, we wanted to find out if using photographs and videos would be an acceptable dietary intake tool. No families objected to taking photographs or video recordings however there were cultural events that made it difficult for all meals on all days to be captured using this method alone.

Breast feeding was not photographed or video recorded by any of the families, however mothers were happy for the researchers to photograph or video if they were breast feeding when the researchers visited. Participants were eager to use the equipment and expressed their enjoyment of filming family members. At the end of the food diary collection period participants said they would use this method again if asked. In future we would recommend that the dietary intake be collected over 1-2 weeks and not necessarily on consecutive days.

Anaemia health literacy for community members and health practitioners was explored through a number of focus groups and individual interviews. Very few community members or health practitioners declined to be interviewed, however not all interviewees participated in the discussions. The community members had a broad range of knowledge about anaemia that improved if they had personal experience with anaemia. Community members in general were aware of the causes, symptoms and treatments for anaemia with diet as the main focus for preventative and curative measures.

Health practitioners had a varied level of knowledge about anaemia in adults and children which in general was reflective of the position they held in the health service. The community member knowledge was reflective of that provided by the Health Practitioners, however the Health Practitioners knowledge was assessed using the CARPA Standard Treatment Manual and the CARPA Reference Manual which requires more indepth knowledge of anaemia than that expected of the community members.

Despite a good level of community anaemia health literacy there was little evidence from the dietary intake collected that the knowledge was put into practice; this finding

has been reported in other nutritional studies.[16, 17] Despite reported improvements in nutrition knowledge and cooking skills, the ability of participants to implement desired dietary changes varied. Previous studies conducted by Investigators Liberato and Brimblecombe found that further exploration of how often iron rich foods should be consumed would be beneficial as well as exploring the barriers to accessing these foods. With the increasing availability and affordability of healthy food options in local community stores a randomized controlled trial is currently being implemented to determine if a reduction in healthy food prices influences dietary behaviour changes in remote Aboriginal communities.[18]

The introduction of electronic health records has greatly improved the generation of recall lists to follow-up participants that have been flagged for review. From the health practitioners interviewed a number of different ways to enter data and generate recalls were described. A standard procedure for entering data and generating recalls with improvements to the prompts that incorporate the recommended treatment and brief interventions from CARPA guidelines would assist the health practitioners to implement what is recommended in the guidelines more effectively.

The introduction of continuous quality improvement (CQI) activities in health services has helped to identify and address systematic barriers and areas of poor adherence to best practice guidelines for some, but not all commonly seen conditions. This process enables health services to monitor best practice and make improvements where gaps exist.[19] This knowledge and resource development project has provided a piloted questionnaire to use with health practitioners and community members to identify knowledge gaps in relation to childhood anaemia.

5 LIMITATIONS

Recording nutritional intake may have influenced how families ate, however as most did not receive an adequate amount daily we don't believe this has influenced the results overall, except for the one child that did have an adequate daily intake. The mother of this child had attended the CII_CHR training and had asked one of the researchers for \$50 so she could buy food for the collection period. Another family did not have power to charge the videoing equipment so a power card was supplied which may have influenced how that family ate for the collection period but not what they would normally have eaten when they have power.

LBD and RGD conducted the interviews in language and then transcribed them into English for analysis. As neither of the researchers are trained interpreters and had a personal involvement in the data collection there is the potential that some of the responses may have been an interpretation of what was said and not a literal translation.

This was a small project to pilot different collection methods for nutritional intake and health literacy knowledge in one remote Aboriginal community which may limit the generalization of the finding.

6 RECOMMENDATIONS

6.1 Photo graphing and video recording

- 1) Is used in conjunction with a daily visit to accurately record the dietary intake of young children.
- 2) The dietary intake is collected over 1-2 weeks and not necessarily on consecutive days.
- 3) Improve use of measuring devices to accurately reflect how much intake is consumed.
- 4) Explore new recoding methods to make it easier to capture all meals, ie. lanyard around the neck with SenseCam device.
- 5) Encourage all family members to take photographs/videos.

6.2 Anaemia health literacy knowledge

- 1) Development of an anaemia education module for remote health practitioners to be completed within three months of their first rural or remote health placement (Appendix 9 – Anaemia education module for health practitioners).
- 2) Improve community knowledge of long term implications of anaemia particularly the impact on physical growth and cognitive development for children. Suggested forums: parenting groups, child health checks, information sessions by community health workers or health promotion staff.

6.3 Implementation of CARPA anaemia guidelines

- 1) Modify interview guide for future use in exploring the low implementation of childhood anaemia screening and treatment guidelines in conjunction with a CQI model to identify what areas of the guidelines require improvement.
- 2) Improve the electronic record systems to include prompts that align with the CARPA guidelines.

7 CONCLUSION

The Childhood Anaemia - Knowledge and Resource Development project was able to establish that photographing or video recording meals was an acceptable methodology to use with families in remote Aboriginal communities. When combined with a food record collected daily, a comprehensive overview of nutritional intake was captured, providing evidence that has not been collected previously to guide nutritional prevention and management strategies. Focus groups and individual interviews conducted with community members and health practitioners obtained informative responses on anaemia health literacy knowledge. These responses have provided preliminary insights to barriers affecting the implementation of anaemia screening and treatment guidelines that can be used as a management strategy to identify educational opportunities for community members and health practitioners.

Anaemia is a complex condition with multiple risk factors associated with the development of disease throughout the life span. Risk factors commence at conception and continue throughout adulthood providing a number of opportunities to introduce prevention and management strategies. With high childhood anaemia rates in the NT and poor implementation of best practice screening and treatment guidelines, innovative and culturally acceptable prevention and management strategies are needed.

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9 Appendices

9.1 Appendix 1 – Training Timetable

27th March 2013 – Day 1

Menzies- Winnellie

Time	Session	Trainer	Attending
9.00- 10.30	Welcome Childhood Anaemia overview	TK Felicity Stef	Roslyn, Bundhala & George
10.30-12.00	Filming families feeding	Sarah Mares	George, Roslyn, Bundhala, Stef, Fliss, TK
12.00-12.30	Lunch- Hungry Hearts Catering		
12.30-2.30	Mandatory reporting	Niki Patmios	Roslyn, George, Felicity, TK, Stef, Bundhala
2.30-4.30	Focus Group Training	Bonnie Moss	Roslyn, George, Bundhala, TK, Felicity & Stef,

28th March 2013 – Day 2

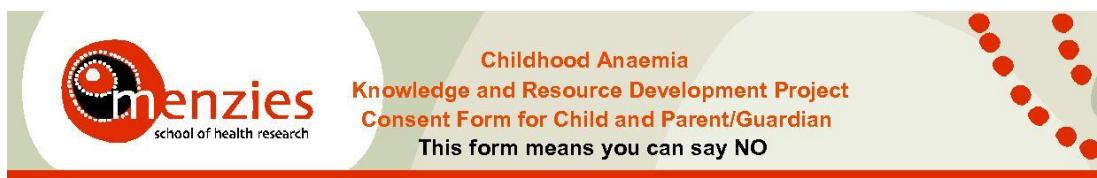
Menzies- JMB

Time	Session	Attended
9.00- 11.00	Discuss HLTAHW301B – Work in Aboriginal and/or Torres Strait Islander Primary Health Care context with Lindy and Loarraine <ul style="list-style-type: none"> • History of remote community region • Traditional foods • Traditional medicine • Work cross culturally 	TK, Felicity, Roslyn & George
11.30-13.00	Discuss CHCPROM401C – Share health information <ul style="list-style-type: none"> • Identify gaps in health information • Identify key people in the community • Consent process • Participant Information Sheet 	TK, Felicity, Roslyn Bundhala & George
13.00-14.00	Lunch	
14.00-16.00	ARDS- Anaemia DVD	All

9.2 Appendix 2 – Timetable for the delivery of CII_CHR and Nutrition unit

Timetable for Certificate II in Child Health Research - Galiwin'ku					
	Monday	Tuesday	Wednesday	Thursday	Friday
9am - 11:00am	TK and Felicity Housekeeping TK- HLTAHW301B Establish agent of disease transmission and mode of control	Lindy and Lorraine - HLTAHW301B Work in Aboriginal and/or Torres Strait Islander Primary Health Care context.	Stef-ChCPROM401C Share Health Information	Felicity- BSBWOR202A Organise and complete daily work activities.	1/04/2013 Foodworks - Selma
11:00-11:30am	Morning Tea	Morning Tea	Morning Tea	Morning Tea	12/04/2013 Foodworks - Selma + Felicity
11:30 - 1:00pm	TK- HLTAHW301B Establish agent of disease transmission and mode of control	Lindy and Lorraine - HLTAHW301B Work in Aboriginal and/or Torres Strait Islander Primary Health Care	Stef-ChCPROM401C Share Health Information	Serving sizes - Selma	
1:00 - 1:30pm	Lunch	Lunch	Lunch	Lunch	
1:30 - 3:30pm	TK- HLTAHW301B Establish agent of disease transmission and mode of control	Lindy and Lorraine - HLTAHW301B Work in Aboriginal and/or Torres Strait Islander Primary Health Care context.	Stef-ChCPROM401C Share Health Information	Foodworks - Selma + Felicity Learn how to use video, photographic equipment and how to download. Consent form/ Info Sheet Felicity	
	Monday	Tuesday	Wednesday	Thursday	Friday
9am - 11:00am	15/04/2013	16/04/2013	17/04/2013	18/04/2013	19/04/2013
	Collect data for HLTAHW407B and BSBWOR2022A,	Collect data for HLTAHW407B and BSBWOR2022A,	HLTAHW407B Go, Grow & Glow, Core Food Groups - Selma	Cooking and storage of foods in the home - Selma	Analysis of foodworks data and report generation - Selma
11:00 - 11:30am					
11:30 - 1:00pm	Collect data for HLTAHW407B and BSBWOR2022A,	Collect data for HLTAHW407B and BSBWOR2022A,	Age Group Diets - Selma	Health Programs in the NT - Selma	Feedback to families - Selma
1:00 - 1:30pm					

9.3 Appendix 3 – Child and Parent/Guardian Consent Form



My name is _____, I am the parent or guardian
Print Your Name

of _____ and.....
Print Your Child's Name

- I have read and understand the Childhood Anaemia – Knowledge and Resource Development Project Information.
- I know it's OK to say NO to this research and that, if I say YES, I can change my mind later.
- I agree to record my child's food and beverage intake using a video/photographic device.
- I know all information collected about my child will be kept strictly confidential.
- I know the possible benefits and risks of being involved.
- I agree to participate in a focus group discussion about childhood anaemia.

I give permission for my childto: (please tick Yes or No)
(Child's name)

1) Participate in the Childhood Anaemia Project..... ↗ Yes No



2) Have photographs and/or videos taken as part of the food diary ↗ Yes No

I consent to:

3) Participate in the focus group discussions about childhood anaemia ↗ Yes No

4) Photographs and/or videos of the focus group discussion ↗ Yes No

Consent for future use:

5) I also give my permission for the study team to:

- Use results from the Childhood Anaemia study in future projects/research related to this study..... Yes No



Participant's signature _____

Team Member's signature _____

Interpreter / Impartial Witness's signature
(please circle as appropriate. Write N/R if not required)

_____ / _____ / _____
Date by Participant

_____ / _____ / _____
Date by Team Member

_____ / _____ / _____
Date by Interpreter / Impartial Witness

Issues or concerns

Please feel free to contact members of our study team if you have any questions about the study.

Therese Kearns (TK) at Menzies School of Health Research Ph: (08) 89228196

If you have any concerns or complaints about your rights or the conduct of the study you may contact the Ethics Committee Secretary at ethics@menzies.edu.au Ph 8922 7922.

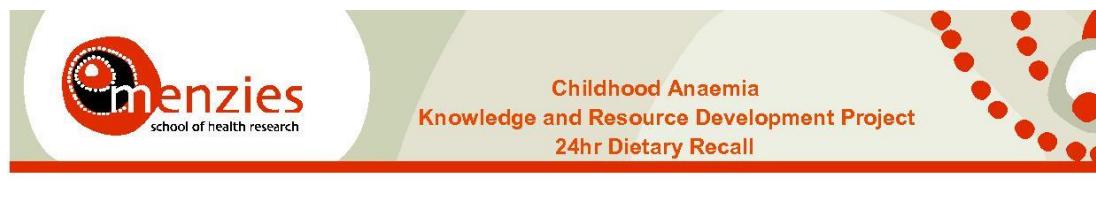
Childhood Anaemia – Knowledge and Resource Development Project
 Consent Child Parent v2_20_3_13



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9.4 Appendix 4 – 24hr Dietary Recall form



ID participant: _____ Date: _____

What did you eat yesterday?

Breakfast

_____ Amount: _____
_____ Amount: _____
_____ Amount: _____

Before mid day

_____ Amount: _____
_____ Amount: _____

Lunch time

_____ Amount: _____
_____ Amount: _____
_____ Amount: _____
_____ Amount: _____

After lunch time

_____ Amount: _____
_____ Amount: _____

Night

_____ Amount: _____
_____ Amount: _____

Before going to bed

_____ Amount: _____

9.5 Appendix 5- Focus Group Consent Form



My name is _____ and.....
Print Your Name

- I have read and understand the Childhood Anaemia – Knowledge and Resource Development Project Information.
- I know its OK to say NO to this research and that, if I say YES, I can change my mind later.
- I know the possible benefits and risks of being involved.
- I understand that participation is voluntary.
- I agree to participate in a focus group discussion about childhood anaemia.
- I agree to maintain the confidentiality of information discussed during the focus group.

I consent to: (please tick Yes or No)

- | | |
|----------------------------------------------------|------------------------------------------------------------|
| 1) Have my photograph taken during the focus group | ↳ Yes <input type="checkbox"/> No <input type="checkbox"/> |
| 2) The focus group being video recorded. | ↳ Yes <input type="checkbox"/> No <input type="checkbox"/> |
| 3) Participate in the focus group discussion. | ↳ Yes <input type="checkbox"/> No <input type="checkbox"/> |



Consent for future use:

- | | |
|-------------------------------------------------------------------------------------------------------|----------------------------------------------------------|
| 4) I also give my permission for the study team to: | |
| • Use results from the Childhood Anaemia study in future projects/research related to this study..... | Yes <input type="checkbox"/> No <input type="checkbox"/> |



____ / ____ / ____
Participant's signature

____ / ____ / ____
Team Member's signature

____ / ____ / ____
Interpreter / Impartial Witness's signature
(please circle as appropriate. Write N/R if not required)

Date by Participant

Date by Team Member

Date by Interpreter / Impartial Witness

Issues or concerns

Please feel free to contact members of our study team if you have any questions about the study.
Therese Kearns (TK) at Menzies School of Health Research Ph: (08) 89228196

If you have any concerns or complaints about your rights or the conduct of the study you may contact the Ethics Committee Secretary at ethics@menzies.edu.au Ph 8922 7922.

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9.6 Appendix 6- Health Service Consent Form

 **Childhood Anaemia
Knowledge and Resource Development Project
Consent Form for Health Services**

This form means you can say No

My name is _____ and ...
Print your name

- I have read and understand the Childhood Anaemia-Knowledge and Resource Development Project Information Sheet.
- I know it's OK to say NO to participation in this project and that, if I say YES, I can change my mind later.
- I know all information discussed with me will be kept confidential.
- I know the possible benefits and risks of being involved.

I give my permission to: (please tick Yes or No)

1) Participate in interviews or focus group discussions	↳ Yes <input type="checkbox"/> No <input type="checkbox"/>
2) Be video/audio recorded as part of the interviews/focus group discussions	↳ Yes <input type="checkbox"/> No <input type="checkbox"/>
3) I freely give my consent	
<ul style="list-style-type: none">to participate in the Childhood Anaemia project andto use results from the Childhood Anaemia study in future projects/research related to this study	Yes <input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/>
	

Participant's signature _____

Team Member's signature _____

Interpreter / Impartial Witness's signature _____
(please circle as appropriate. Write N/R if not required)

____ / ____ / ____
Date by Participant

____ / ____ / ____
Date by Team Member

____ / ____ / ____
Date by Interpreter / Impartial Witness

Issues or concerns

Please feel free to contact Therese Kearns if you have any questions about the study.

Therese Kearns (TK) at Menzies School of Health Research on Ph 8922 8196.

If you have any concerns or complaints about your rights or the conduct of the study you may contact the Ethics Committee Secretary at ethics@menzies.edu.au Ph 8922 7922.

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9.7 Appendix 7 – Foodworks Report

FOODS

13-apr-13

Breakfast

Breakfast cereal,whole wheat,biscuit,added vitamins b1,b2,b3	45g
Milk,cow,fluid,regular fat (~3.5%)	250g
Fruit drink,25% apple juice	125g
Water,tap	125g

Morning tea

Fruit drink,25% apple juice	125g
Banana,cavendish,peeled,raw	60g
Grape,red globe,raw	60g
Peach,unpeeled,raw	60g
Water,tap	125g

Lunch

Soup,chicken,with noodle,cup of soup,instant dry mix	100g
Potato,pale skin,peeled,boiled	30g
Pumpkin,peeled,boiled	30g

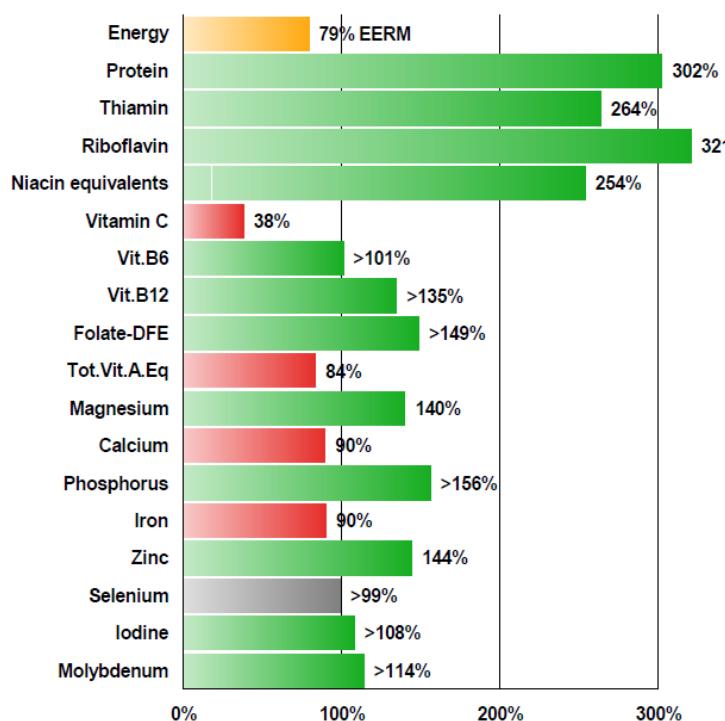
Afternoon tea

Yoghurt,regular fat (~3%),vanilla flavoured	150g
---------------------------------------------	------

Dinner

Bread,damper,added salt,homemade	40g
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RECOMMENDED DIETARY INTAKES (RDI)



[Participant picture removed]	[Participant name removed] is having a little bit from all groups: <ul style="list-style-type: none"> - Fruits - Vegetables - Bread and cereals - Meats - Milk and cheese But not enough foods. He is missing out on Calcium, Iron and some vitamins.
He is having banana, grapes, pumpkin, potato and meat which are good. He needs to have more of these foods.	[Participant picture removed]
	He would be better having milk instead of juice.

Some advices for your child to grow healthy and strong

- give plenty of water
- give him lots of fruits, vegetables and legumes
- avoid sugar and fat foods such as soft drinks and junk foods
- give him foods from all food groups

Cereals and breads

Fruits

Vegetables

Meats

Milk

9.8 Appendix 8 – Question Guide for Community Member Focus Groups

*

- What is anaemia? Weak blood?

Nharru dhuwal anaemia ny?
gulaymirriw?

- Why do you think people have weak blood?

Nthalij yuli ga yalgumy gulaymirriw thior?

- What happens to people if they have weak blood?

Nhadtjanha yuli gulaymirriw nydja yobju?

- How do they fix it?

Nthalij ha yuli manymakthirny djä?

- How do you prevent?

Nthalij ha dhu gulmaramany dhuwaliye
buluyuwny djä marranhawar?

- How do you know if you got weak blood?

Nthalij dhu manygithirny djä nhengunki
ne gulaymirriw nydja?

- How do they treat it? medicine?

Nhadtjan walal ^{dhu} ngontsi ngotti djama (dutmaan)

9.9 Appendix 9 – Anaemia education module for health practitioners

Recommended topics to include in module that should be completed within 3 months of first rural or remote health placement:

- Definition of anaemia, iron deficiency, iron deficiency anaemia,
- Causes of anaemia in adults and children concentrating on the most commonly seen conditions in the NT. eg, anaemia of infection, anaemia of chronic disease, anaemia in pregnancy, iron deficiency anaemia
- Long term effects of anaemia on child development and activities of daily living
- Treatment options and brief interventions from CARPA - use case scenarios to highlight commonly seen situations where CARPA is not followed.
- Follow-up procedures to include how to enter a follow-up for repeat Hb and how to enter a follow-up to return for treatment in electronic health records
- Social aspects of anaemia - how to discuss food security, gambling etc. and what to do/who to refer to.
- Nutrition, what are the commonly available foods and how often should they be eaten
- How to use the anaemia care plan and electronic health record system

This could be delivered as a 2 day workshop or offered as an online module.