

Community-based action research to improve health knowledge: “On Track Watch”

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“That Heart Sickness”: Exploring Aboriginal Young Peoples’ Experiences of Rheumatic Fever Care from Childhood to Adulthood

PhD Study-Alice Mitchell

Supervisors: Dr Suzanne Belton, Dr Vanessa Johnston & Associate Prof Anna Ralph

- 35 Aboriginal young people with ARF or RHD
- 37 others
- 156 days in 4 sites

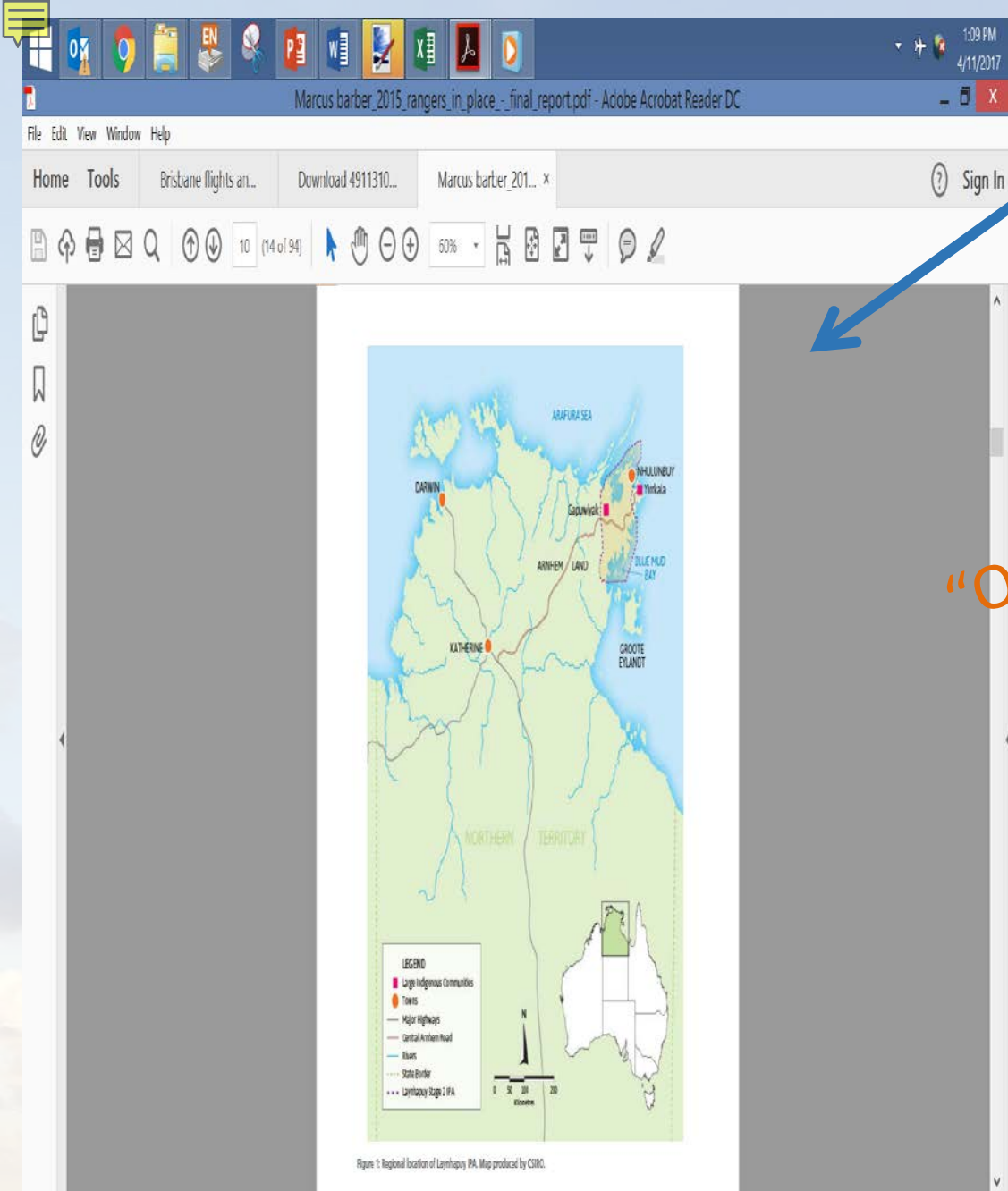
The PhD study was embedded in The Trial:

Improving delivery of secondary prophylaxis for rheumatic heart disease in remote Indigenous communities (the RHDSP trial): outcome of a stepped-wedge, community randomised trial

Ralph AP, de Dassel JL, Kirby A, Read C, Mitchell AG, Maguire GP, Edwards K, Currie BJ, Bailie RS, Johnston V, Carapetis JR.

Improving delivery of secondary prophylaxis for rheumatic heart disease in remote Indigenous communities (the RHDSP trial): outcome of a stepped-wedge, community-randomised trial.

PLOS Medicine



Yilpara was established in 1974. It is one of 30 linked communities in the Laynhapuy Homelands region

“On Track Watch”

“If I don’t do something, there will be no-one here to look after our land”
-Djambawa Marawili, 2015



Certificate II in Community Health Research

CDU-Menzies School of Health Research

15 trainees are in the first research group based in the Laynhapuy Homelands working on a community action research project



First meeting in November 2016



Training started in March 2017



In this site,
there had been
little prior exposure to research





Rheumatic heart disease the Northern Territory

- Aboriginal people are ***55 times more likely*** than non-Aboriginal to die from ARF/RHD
- Is the ***greatest cause of health inequity*** between Indigenous and non-Indigenous Australians, *ahead of renal disease, diabetes and ischaemic heart disease*
- These high rates are important contributors to the ***gap in life expectancy*** between Indigenous and non-Indigenous Australians.



On Track Watch

Large number of people with ARF / RHD in Yilpara

in a population of 100 people,

- There are 6 children who have had ARF and have monthly injections
- There are 6 adults who have RHD
- There are 3 adults who had ARF and have finished 10 years of injections
- Different ways of presenting data





Rheumatic heart disease (RHD)

- ***Rheumatic fever starts with sore throats and skin sores.***

Bukuwarkthundja ṇayi ṇuli rerriya rumbal ṇuli dhulkumiyii wo gurak ṇuli bulyun bala rumbal nhä ṇuli gormuryi.

- ***A germ called ‘strep’ causes these sore throats and skin sores.***

Mewirri yäku ‘strep’ balanya nhakun djetjimiya gurak wo rumbal.

- ***If someone gets rheumatic fever they will need to go to hospital. They need to have a penicillin injection every 4 weeks for about 10 years. If they don’t have the injection they might get Rheumatic heart disease.***

ṇunhi yolṇu dhu märram rerri gormurinyawuy, marrtjin bonḍin bala watjpilil. Bala nhenydhū märraman mirritjin yäku penicillin injection bala nheny dhu manymaknha dhe dhu ga nhina .

- ***Rheumatic heart disease makes our heart sick (valve damage) and after a while our heart may not work properly (heart failure) and we may need an operation.***

ḍoṭurrk’tja rerri ṇayi’tu buyngun manymakgum djäma rumbalṇur.



Why is the community doing this research?

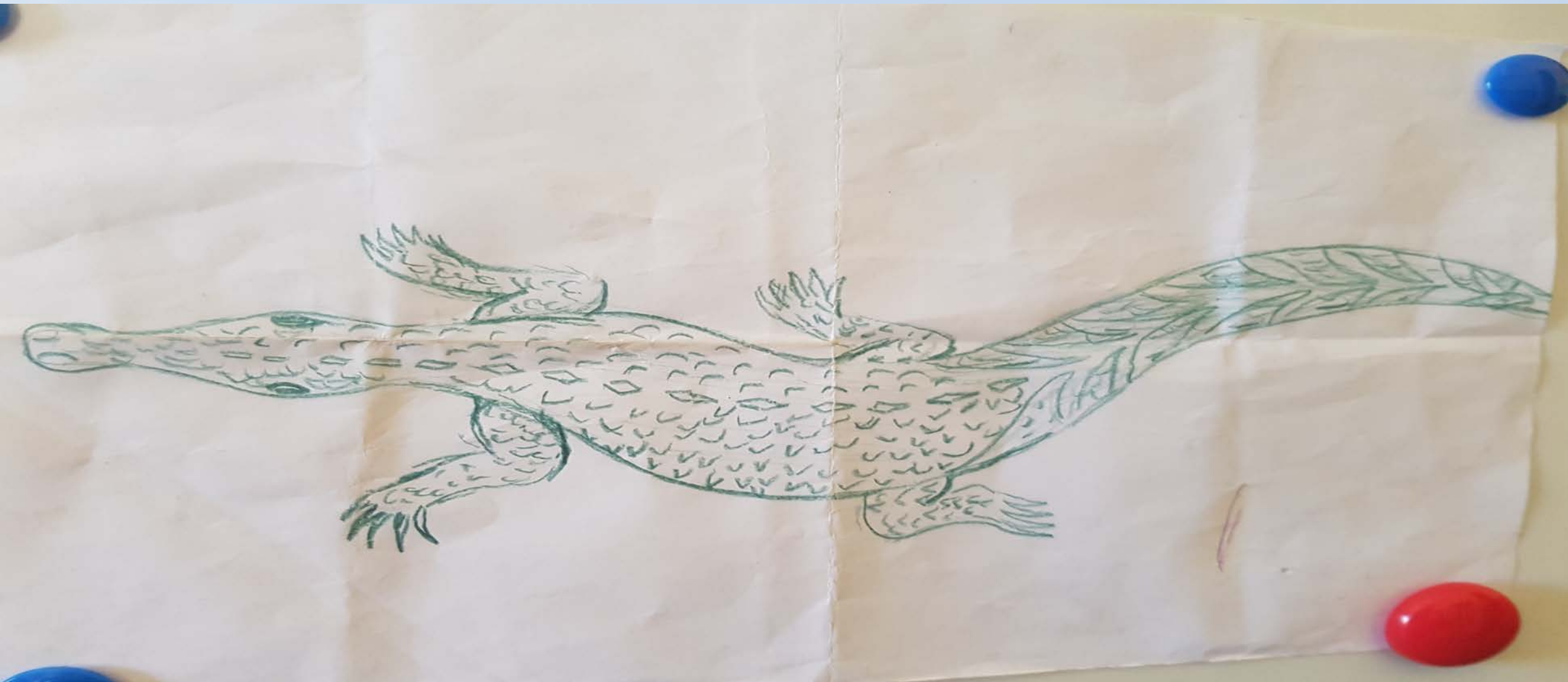
- We don't want our kids to have heart surgery
- To keep the kids healthy, community healthy, look after our land
- All of the On Track Watch group have been through having the injections or have children who are on the injection or already had the operation



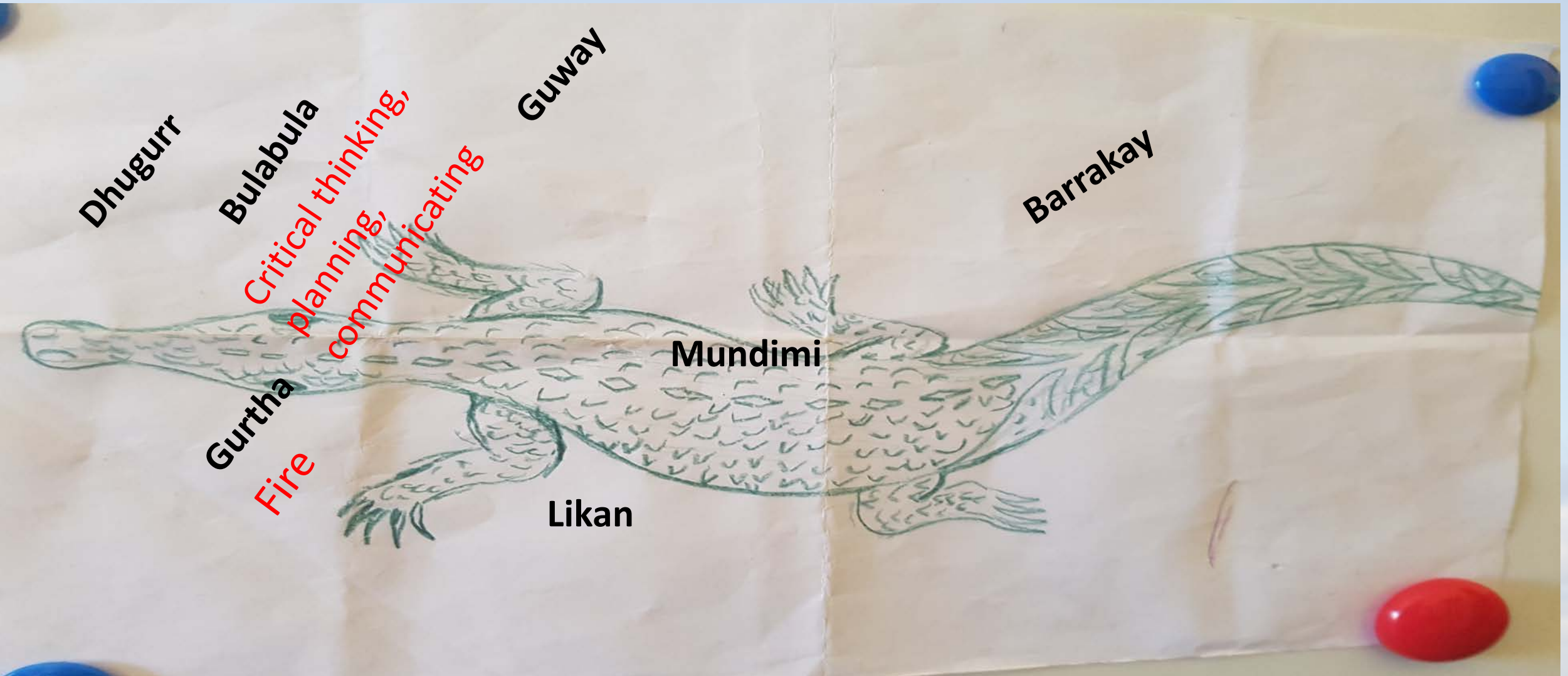
1. Metaphors for knowledge – both way learning



Bäru – crocodile

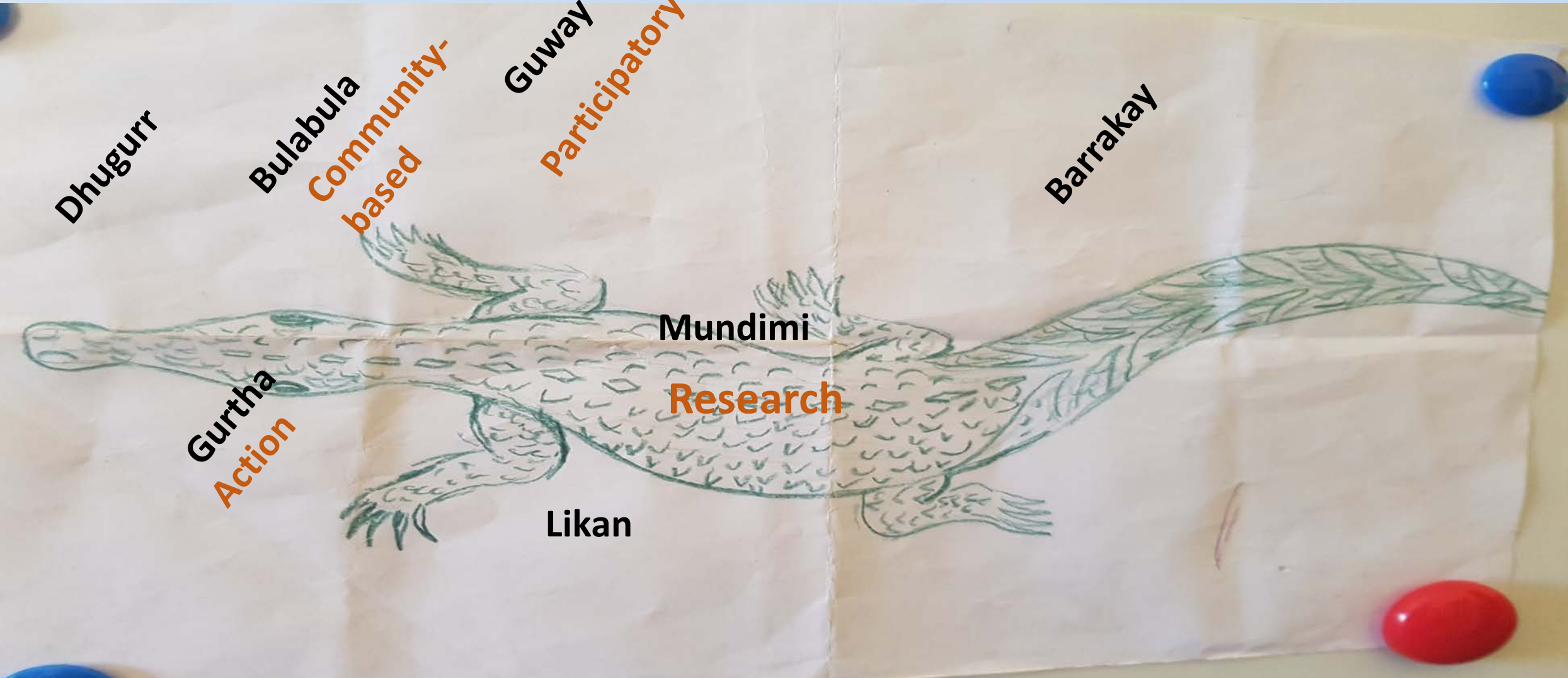


Bäru – a Yolngu knowledge system



Bäru – a Yolngu knowledge system

CBPAR - a Balanda knowledge system



Lipalipa (canoe) – a metaphor for action research

Looking deeply to decide which way to go



Above the surface

Winds
Clouds

**LOOKING AT THE SURFACE OF
THE WATER IS NOT ENOUGH**

Below the surface

Currents
Rocks
Shallow water

For Indigenous painter and clan leader Djambawa Marawili, art carries a lot more meaning than aesthetics alone.

"I don't say this is my art," Mr Marawili says. "I always say, this is my document."

The screenshot shows a web browser window with the address bar displaying the URL: www.smh.com.au/environment/talking-is-not-enough-indigenous-exhibition-reveals-the-legal-power-of-art-20171107-gzgx1s.html. The page content includes a headline, a quote from Mr. Marawili, and a photograph of him standing in front of his artworks. The browser's taskbar at the top shows various open applications and the system clock indicating 8:21 PM on 14/11/2017.

For Indigenous painter and clan leader Djambawa Marawili, art carries a lot more meaning than aesthetics alone.

"I don't say this is my art," Mr Marawili says. "I always say, this is my document."

Djambawa Marawili with artworks by himself, his brother and his father. Photo: Louise Kennerley

<http://www.smh.com.au/environment/talking-is-not-enough-indigenous-exhibition-reveals-the-legal-power-of-art-20171107-gzgx1s.html>



Other metaphors we used- (these are not transferable to other settings)

Yolngu concept*	Balanda concept
Gurrutu (relationship rules)	Ethics and consent
Yinapungabu/Miyarra (coming up/out from beneath - boils, blood, maggots)	Knowledge sharing
Djalkari (foot steps)	Health behaviours - choosing the right path
Wujumugu (dilly bag)	Research tools
Wapitja (digging stick)	Truth - getting deeper knowledge (long yams)
Moieties (there must be balance between the two moieties)	Mixed methods research, good research balances qualitative (word) and quantitative (number) data
Yam leaf confusion	Mistaken immune response to Strep A
Bait for fishing	Different germs cause different diseases

* Permission to share cultural knowledge has been given by senior community leaders

We used both way learning to talk about:

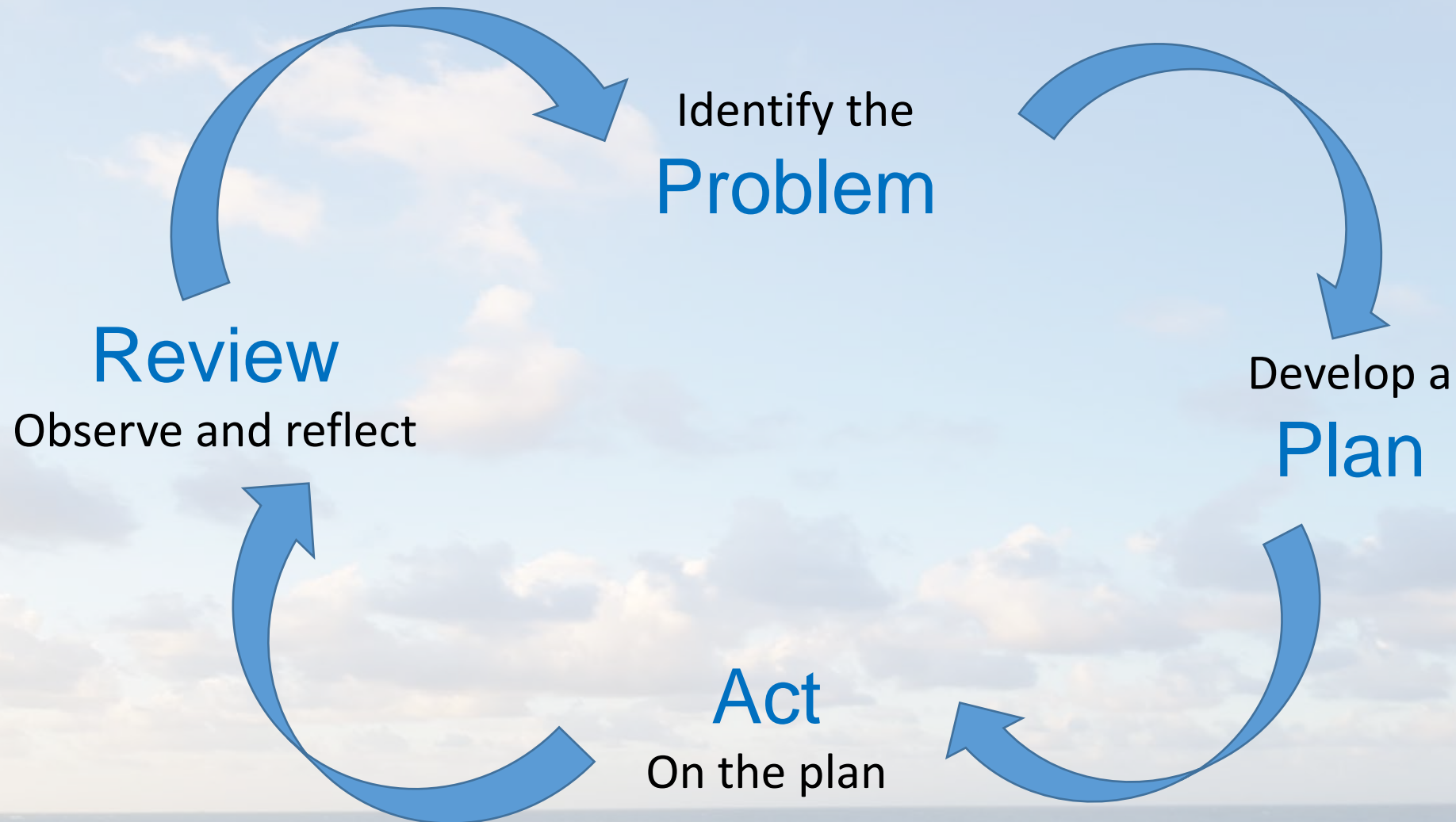
Rheumatic heart disease

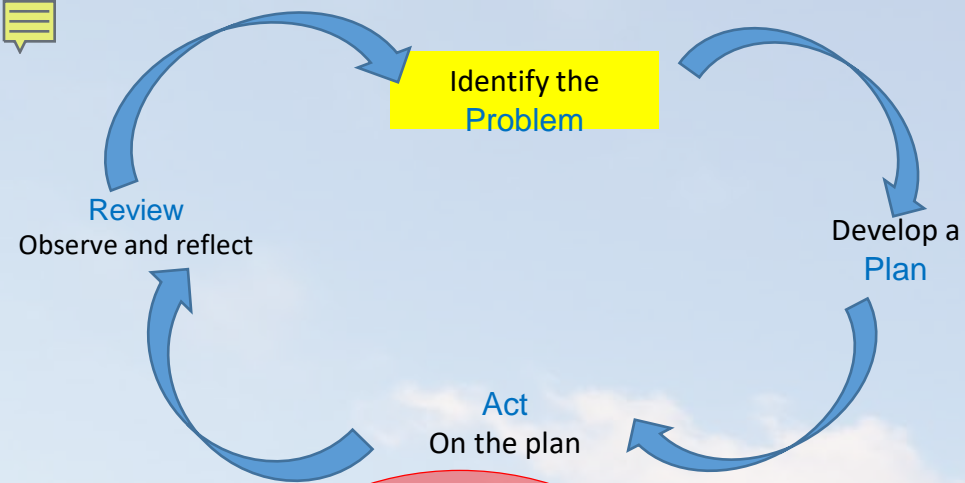
- Strep A Infection
- Immune system
- Rheumatic fever
- Heart disease
- Prevention

Research

- Problem-Plan-Act-Review research cycle
- Research tools
 - focus groups
 - Interviews
 - Swabbing
 - surveys
- Consent
- Ethics

Action research cycle





The community decided on three research areas

Ŋatha - Food

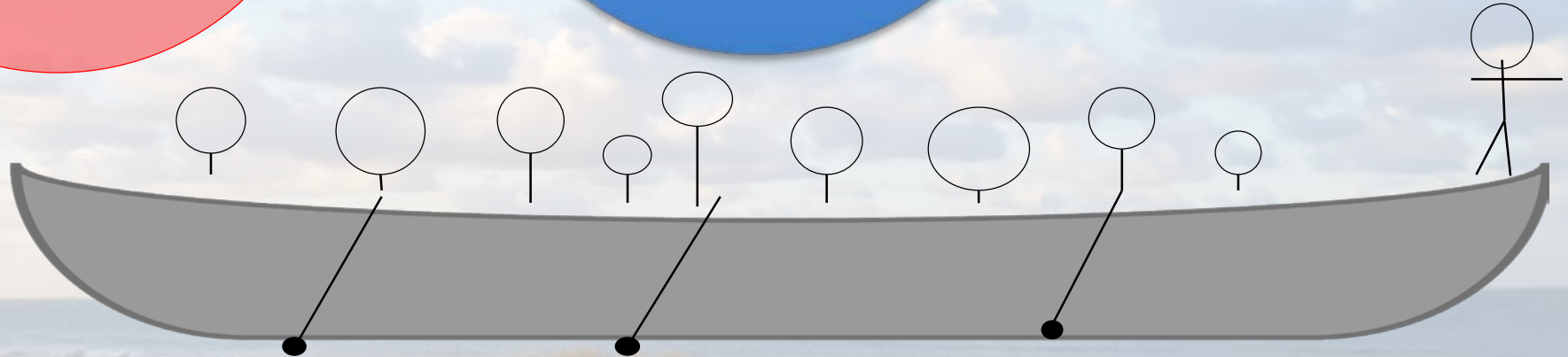
How can we improve the food in Yilpara to make the community healthy and strong?

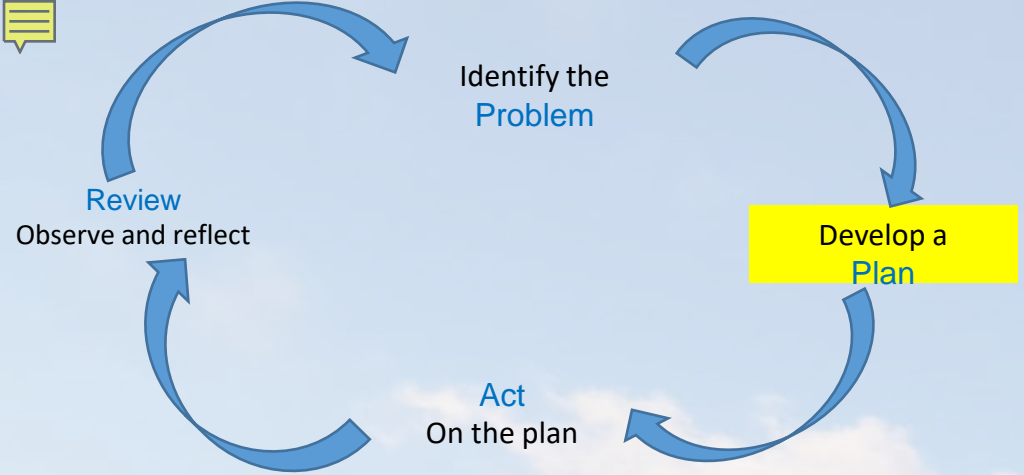
Teenagers' Wellbeing

- How do we understand them
- How do we help them?

Watch out for Strep

- How much strep?
- How do we help to stop it?
- How do we stop germs?
- Swabbing project





And developed three action plans

ηatha - Food

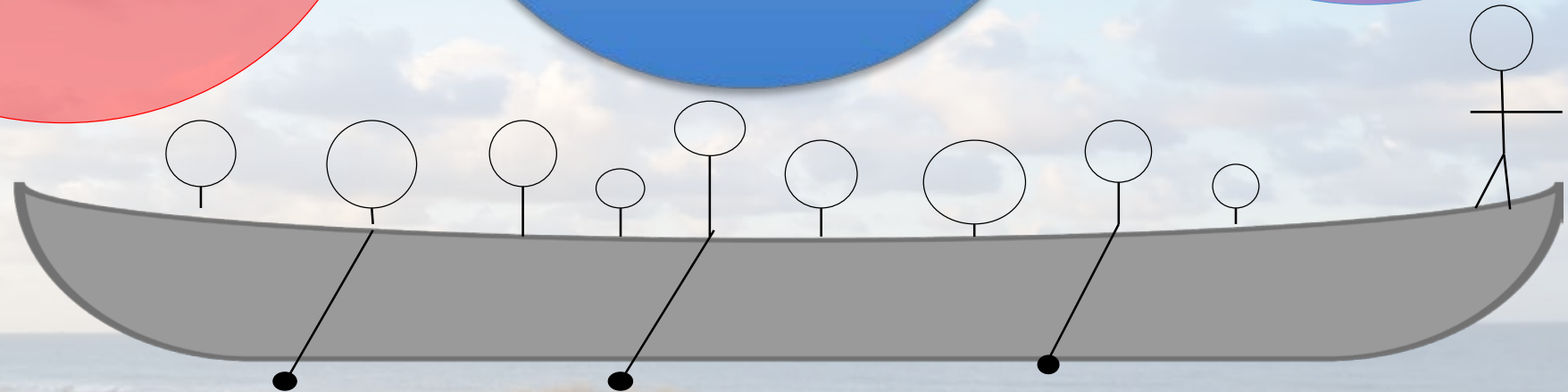
Lunches for school kids and others
Learning about getting money for food for lunches
Understanding what food is in the shop

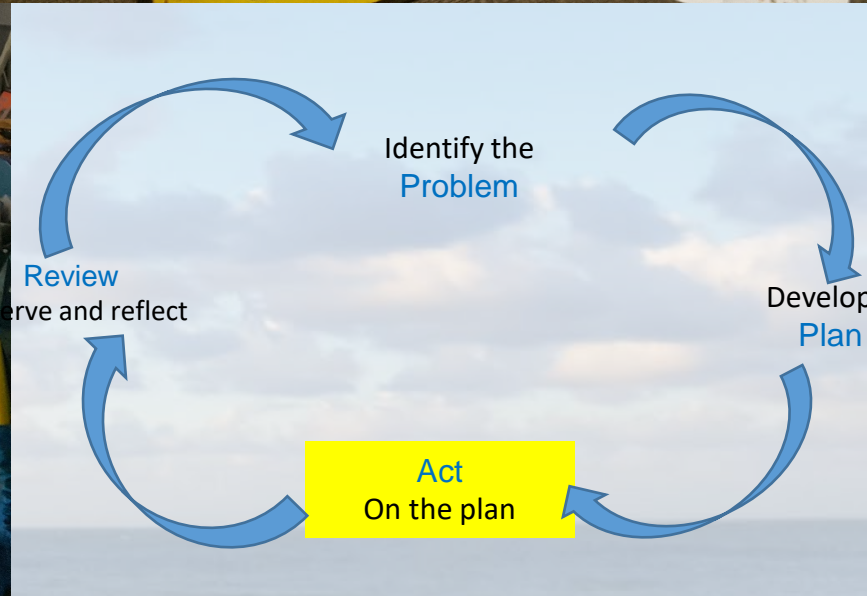
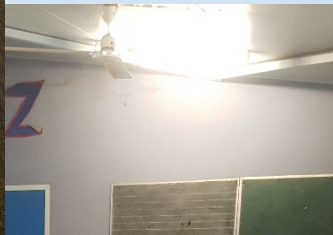
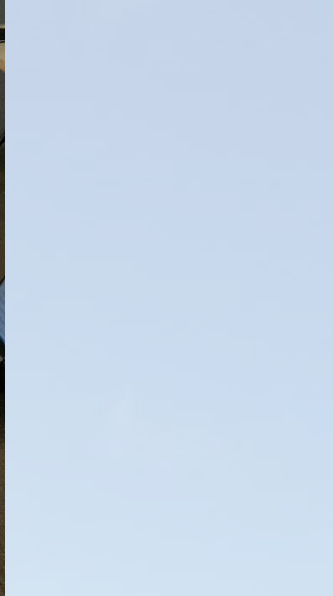
Teenagers Wellbeing

Movie night
Activities – sport, camping, culture, music
Working in partnership with CSP (youth program)
Expert in understanding Teenager; drugs and alcohol

Watch for Strep Infection

Awareness raising
Learning to identify sores and sore throats
Learning about germs
Swabbing for Step A

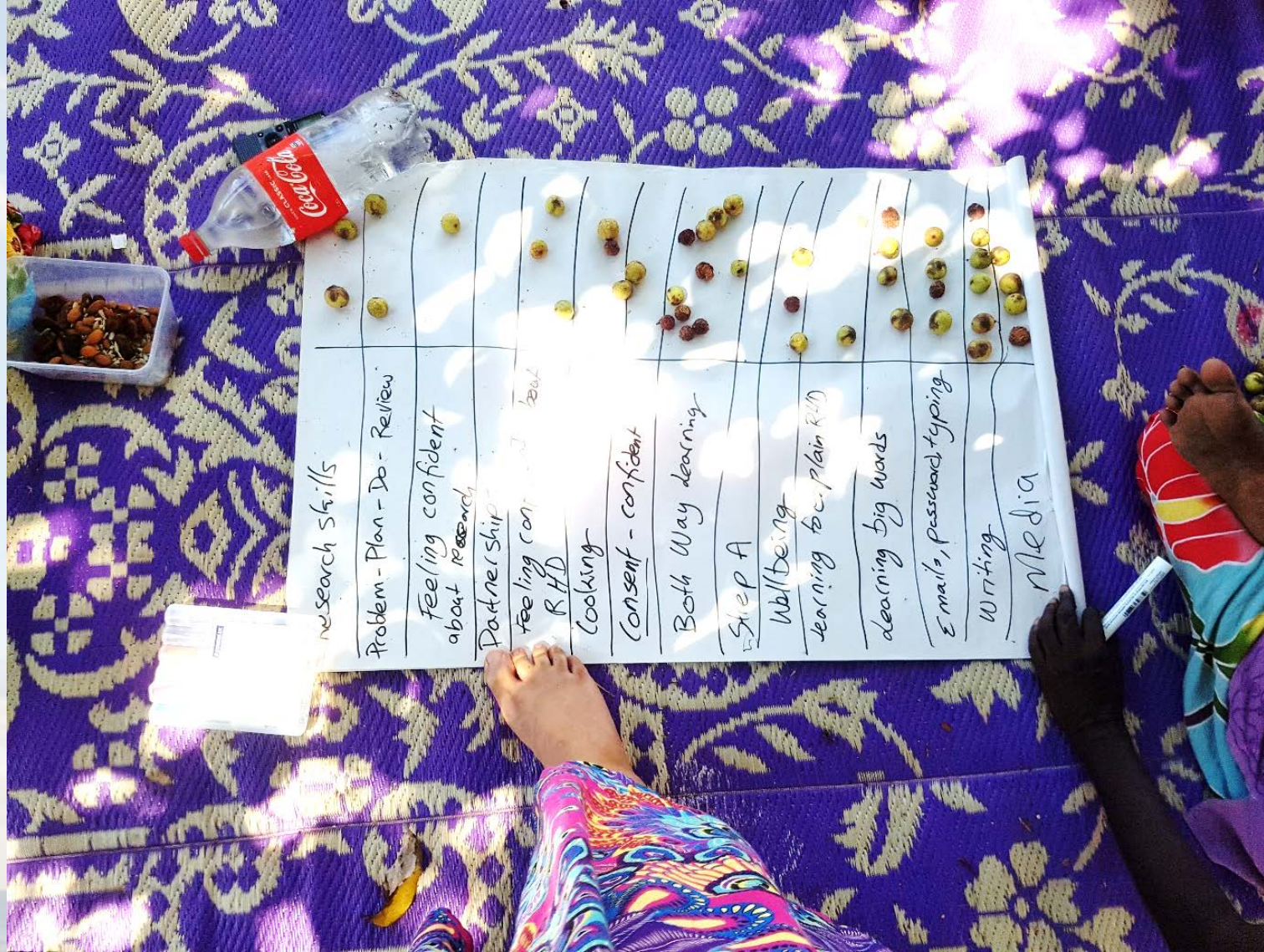




Trainees at
work on the
three
projects



ii) Trainee developed tool - Most important learnings matrix





Most important learnings matrix - analysis of quantitative data

	Votes		Votes
Research skills	2	Strep A	6
Problem-plan-do-review cycle	3	Wellbeing	7
Feeling confident about research	2	Learning to explain RHD	3
Partnerships	1	Learning big words	6
Feeling confident about understanding RHD	3	Emails, internet, typing	7
Cooking	6	Writing	6
Feeling confident about consent	3	Media	5
Both way learning	5		

* 10 participants – 6 votes each



outcomes

Outcomes – 1. Understanding RHD

- ***“It is a new thing that Yolngu are learning to know about germs”***, “about Strep A and the disease it causes”
- At the school we talked to the whole group of parents and children and they felt comfortable and interested when they heard the story
- We told them about the numbers of people with RF and RHD in the community; we explained about the Strep germ
- People were very interested, they listened quietly and asked lots of questions about where Strep came from, where did the disease come from and how do we stop it, how the germs got in the body (we told them about being clean, hygiene, awareness of germs)
- ***We learnt that people didn’t realise the germs are just there***, they thought they came from a long way, but they are living here
- ***I feel very strong now about taking care of djamarkuli***

Outcomes – 2. RHD Knowledge sharing

Sharing new knowledge with others

- ***“Start from our community and work our way outside to help other Homeland communities”*** because RHD is new for us (all) we have to understand how to stop it.
- ***Strep A*** – it is everywhere (germs, hygiene); understanding gives a picture for the community about looking after children
- Opportunities for trainees have included addressing a national RHD workshop, connecting to other Yolngu researchers, developing their own resources and taking OTW to nearby communities.

Asking for more knowledge

- ***“we would like scientists to come and tell us about the different types of germs – the names of different germs”***
- People would like to know what effect germs have in people’s bodies -this is like knowing that different bait live in different places and catch different fish eg small bait at Dhuruputjpi catches cat fish
- It will give Yolngu knowledge to see and understand how the germs live in peoples’ bodies



Outcomes – 3. Research understanding

- “Looking through our own thoughts about how to run the project gives us more understanding about how to run projects in the future”
- Doing this project made me feel good, it is very clear about research
- “It changed my life, on that day I was amazed, I felt really happy” (Wesley, Aboriginal Health worker)
- ***“What I got out of it personally was learning about the Problem-Plan-Do-Review cycle and using it in other areas of my life”*** (Makungun Marika)

Ethics

- People felt good about signing the consent form (after being given good information about Strep)
- The swabbing was done in a good way – in a quiet room
- Good sharing our own knowledge, skills and feelings about ethics and putting Yolngu (gurrutu) and balanda Rom (law) together

Outcomes – 4. Sharing the research understanding

As a result of learning about research the trainees would like to:

- Do any other research in the community (not just health)
- Have more training
- Meeting other Yolngu researchers
- One day working for CDU
- Teach young ones to do the training with CDU, or do some research
- Have Yolngu from other Homelands to join us, and to start their own projects

Outcome – 5. practical skills

- Overall participants most valued OTW for the ***practical skills*** - literacy and using computers
- Literacy – learning big, complex and scientific words
- ***Wellbeing***– a new idea, the things we did changed feelings, learnt how to look after each other, bringing everyone together (eg community BBQ) is good for young people, we have more purpose life
- Cooking program – similar



Outcome - 6. Process learnings

Enablers

- **Both ways learning** - Yolngu and Balanda combine, sharing knowledge together, talking together, sharing ideas; learning about Balanda law, culture, modern world
- Showing **respect**, working together “the right way” – talking, listening, learning, sharing, making time to come to class, showing interest
- **Working in a group** – helping, encouraging each other, “gave me understanding about how to work in a group”.
- interesting work, good training
- **Partnerships**– people feel more comfortable working together, working in a group can build up partnerships, also it is good to get extra help from outside people. A good example was the cooking program was valued highly



Conclusions

There are important connections between:

1. Both-way learning and wellbeing

Not understanding the mainstream world is stressful

2. Action research and community development

Increased knowledge → capacity building → community building

3. Research skills and critical thinking

Valued by community leaders making decisions about a new Corporation
(*unfamiliar mainstream governance rules etc*)

4. Understanding and knowledge sharing (translation)

Understanding empowers community to take action to share knowledge

- What we are doing is showing young ones, showing others, they are watching us to understand the ways of doing research. Learning about deeper meanings and understanding
- Dhuwaya balanya mayali nhakun milkuma rom yuṭawu yolṇuwu marṇgithinyarawu ga nhäma ṇiṇ-thun ga maladjarr'yun nhä ṇayi dhukarr dhunupa ga mayali ṇali yurru malṇ'thun mama balakuwitjan djämagu research

“The project was a new experience for Yilpara, and we will go to other places and teach them, keep on going!” (Community researcher)

Thank you to:

- Local community leaders
- The other OTW trainees
- Yilpara community for being part of the research
- Dr Anna Ralph, Alice Mitchell, Jeff Cook (co-authors)
- The Menzies trainers – Jodi Phillips, Clarissa Carter
- Laynha Health, especially Yilpara clinic
- Baniyala (Yilpara) School
- Miwatj Employment Participation
- Children in Schools Program (Laynha)
- Laynha Rangers
- Menzies School of Health Research; Charles Darwin University (CDU)
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