

Research involving Aboriginal and Torres Strait Islander peoples – Ethics issues, processes and reflections

Michael Martin

Chair, ANU Human Research Ethics Committee

Acknowledgement of Country

We acknowledge and celebrate the First Australians on whose traditional lands we meet, and pay our respect to the elders past, present and emerging.

Common Issues and Questions

- Full Ethics review is required – is there “low risk” research involving Aboriginal and Torres Strait Islander peoples?
- Research involving Aboriginal and Torres Strait Islander peoples needs to be about issues that are important to Aboriginal and Torres Strait Islander people
- “Involving” – simple word, complicated meaning...
 - Aboriginal and Torres Strait Islander peoples as research participants (partners)
 - Focus on issues that affect Aboriginal and Torres Strait Islander peoples
- Health research – why is it different?
- Consultation? Engagement? Who speaks for whom?
- Agreements – “Benefits and sharing”, “Research Agreements”
- Cultural knowledge and Intellectual Property
- Research Governance – Advisory groups

Key Resources

- *National Statement on Ethical Conduct of Human Research* (NHMRC):
<https://www.nhmrc.gov.au/about-us/publications/national-statement-ethical-conduct-human-research>
 - Chapter 4.7
- *Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders* (NHMRC):
<https://www.nhmrc.gov.au/about-us/resources/ethical-conduct-research-aboriginal-and-torres-strait-islander-peoples-and-communities>
 - Maps to the National Statement
- *Keeping Research on Track II* (NHMRC):
<https://www.nhmrc.gov.au/about-us/resources/keeping-research-track-ii>
 - “How to” guide for research based on the document above
- *Guidelines for Ethical Research in Australian Indigenous Studies* (AIATSIS):
<https://aiatsis.gov.au/research/ethical-research/guidelines-ethical-research-australian-indigenous-studies>
 - Updated Guidelines from AIATSIS coming soon

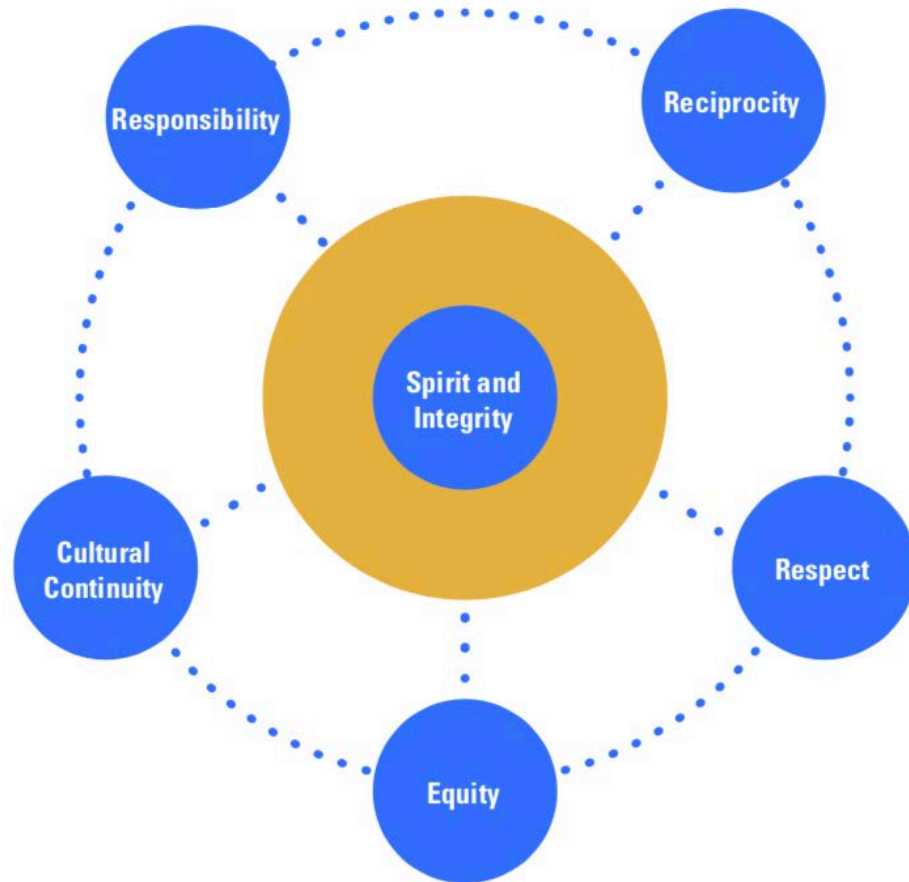
Another resource – the dilly bag

- The ARPNet Dilly bag. A practical field guide to participatory and other research tools for use by Aboriginal research practitioners in Australia
<https://www.researchgate.net/publication/302957598> The ARPNet Dilly bag A practical field guide to participatory and other research tools for use by Aboriginal research practitioners in Australia

The National Statement

- “There should be evidence of support for the research project from relevant Aboriginal and Torres Strait Islander communities or groups and the research methodology should engage with their social and cultural practices.” (4.7.2)
- “The benefits from research should include the enhancement or establishment of capabilities, opportunities or research outcomes that advance the interests of Aboriginal and Torres Strait Islander Peoples.” (4.7.7)
- “The research proposal should demonstrate evidence of respectful engagement with Aboriginal and Torres Strait Islander Peoples.” (4.7.10)
- “The research approach should value and create opportunities to draw on the knowledge and wisdom of Aboriginal and Torres Strait Islander Peoples by their active engagement in the research processes, including the interpretation of the research data.” (4.7.11)

Full Ethics review is required – is there “low risk” research involving Aboriginal and Torres Strait Islander peoples?



It's not so much about “risk” as it is about the research being designed around core values (reciprocity, respect, equality, responsibility, survival and protection, spirit and integrity)

“Involving” – simple word, complicated meaning...

- “Involving” means Aboriginal and Torres Strait Islander peoples as
 - Research leaders
 - Research partners
 - Participants in research
- Research about topics that affect Aboriginal and Torres Strait Islander peoples “involves” Aboriginal and Torres Strait Islander peoples

Consultation? Engagement? Who speaks for whom?

- Probably the single biggest issue the HREC thinks about...
- Scope of research: is it community-based? Issue-based? Health-related?
- Consultation: the idea is NOT that researchers “consult” and then decide approaches based on the information provided. This is too one-way.
- Research not *about* but *with*
- Engagement: Who leads the research?
- Letters of support – from whom?
- Evidence of engagement

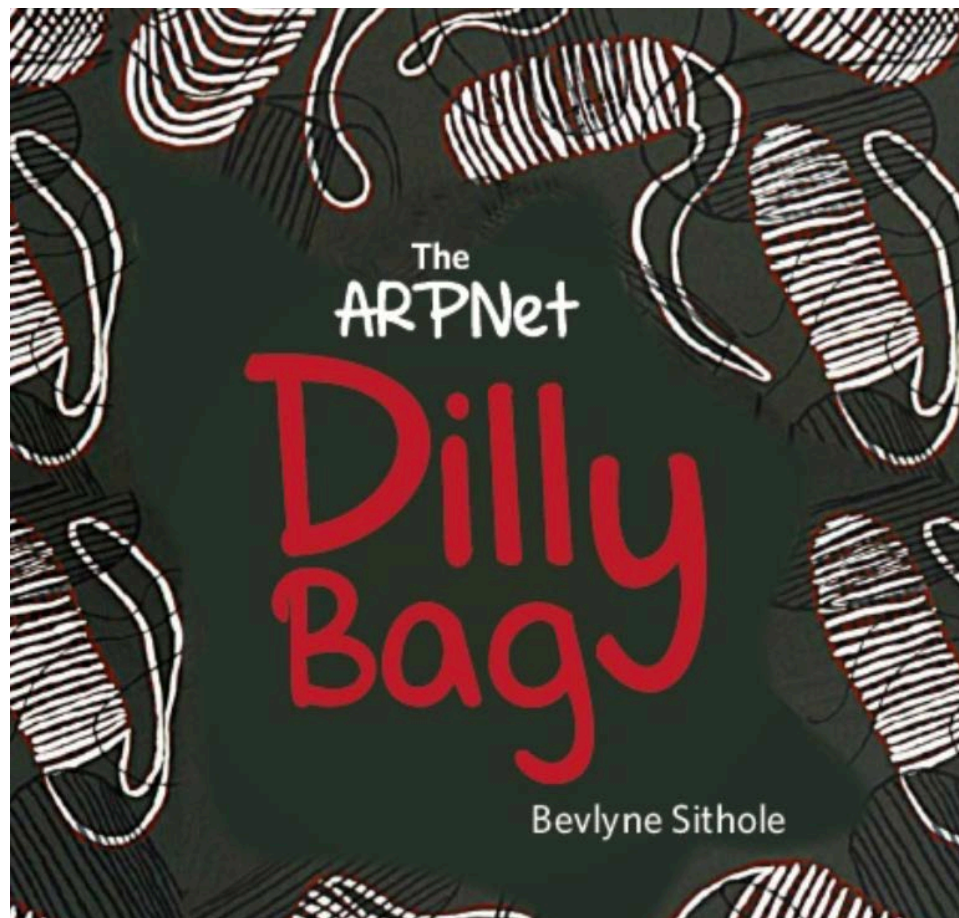
Agreements

- Research agreements. Evidencing that benefits and risks have been discussed and agreed.
- Benefits and sharing agreements. Ensuring that “the realisable benefits for Aboriginal and Torres Strait Islander participants from the research processes, outcomes and outputs should be distributed in a way that is agreed to and considered fair by these participants” (NS 4.7.9)
- Agreements need to be
 - Specific
 - Enforceable
 - Comprehensive: “A letter of community or organisation support for the project should not be provided if people are not happy with every detail of the research project. It may be beneficial to wait until the necessary changes have been made and agreed to by all parties” (*Keeping Research on Track II*, p. 30).

Cultural Knowledge and Intellectual Property

- Typical Intellectual Property policies may not be “fit for purpose” in research involving Aboriginal and Torres Strait Islander peoples as they tend to vest IP in researchers, institutions and contracting organisations.
- Where IP is created by Aboriginal and Torres Strait Islander peoples and where cultural knowledge is involved, all rights (copyright, moral rights, intellectual property rights) should vest in Aboriginal and Torres Strait Islander people and organisations, and benefits should flow to Aboriginal and Torres Strait Islander people.

More about the dilly bag – Read it!!



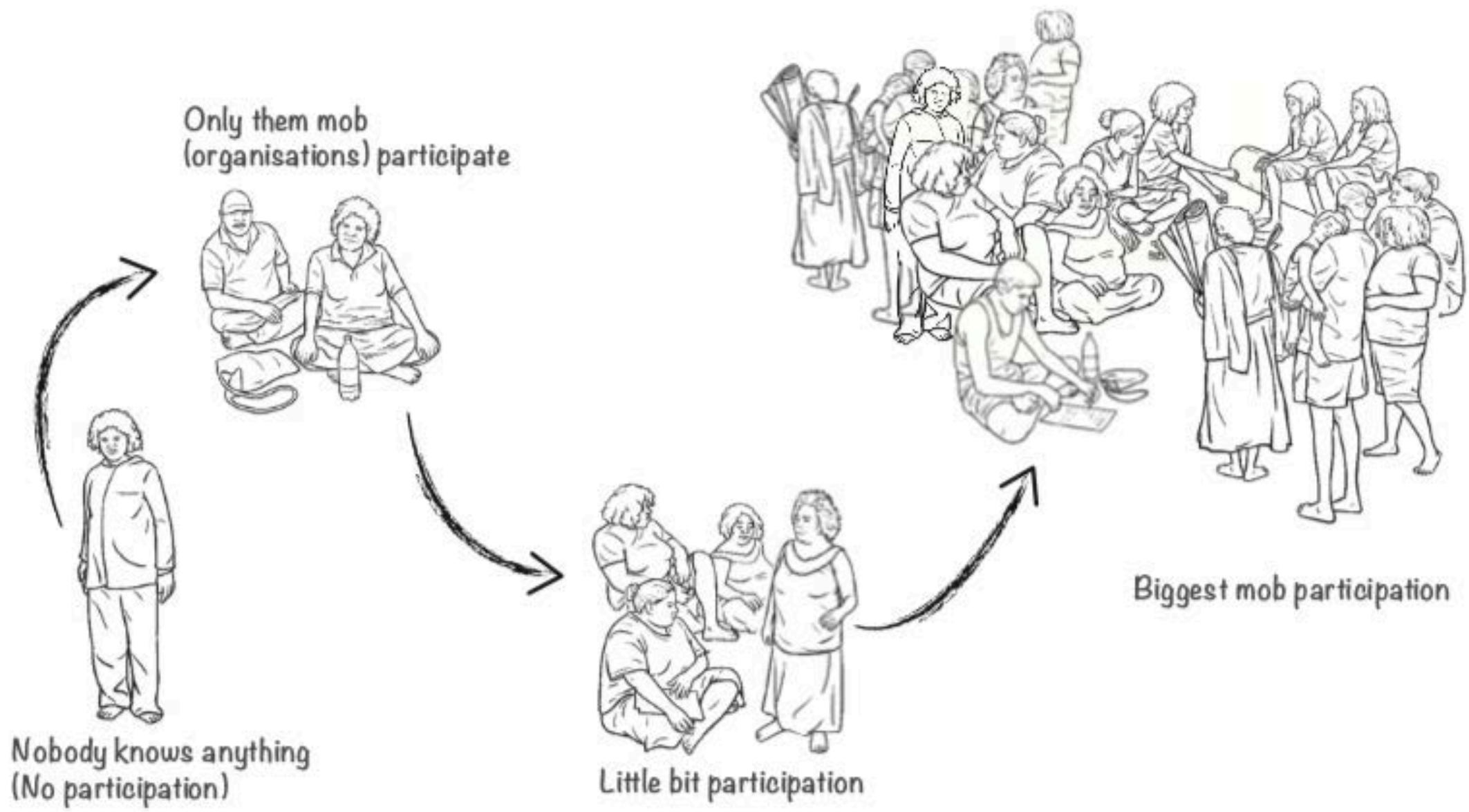


Figure 1. Levels of participation that you can expect to get when you are on the job.

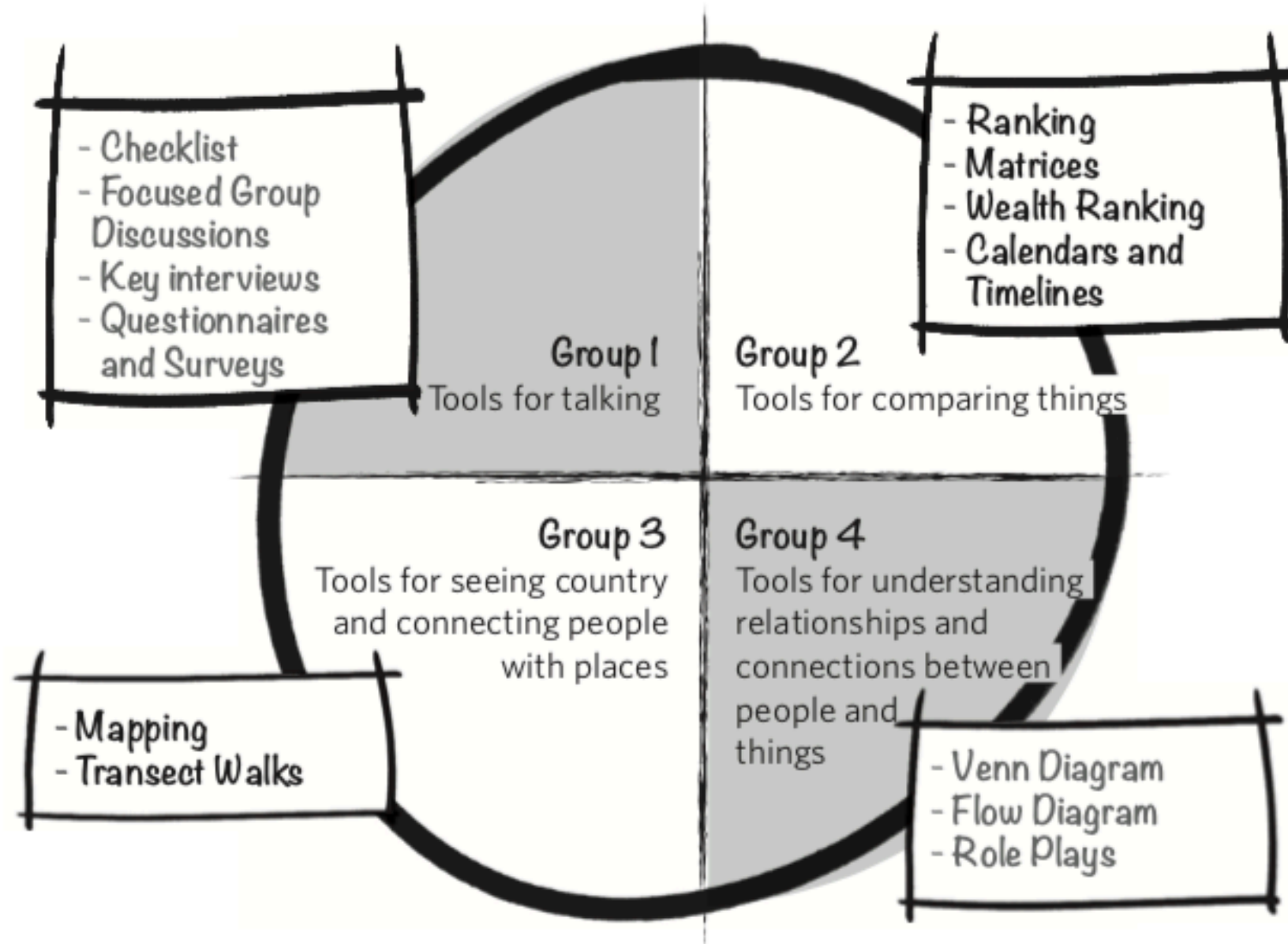


Figure 2. Suggestions about which tools work well together.

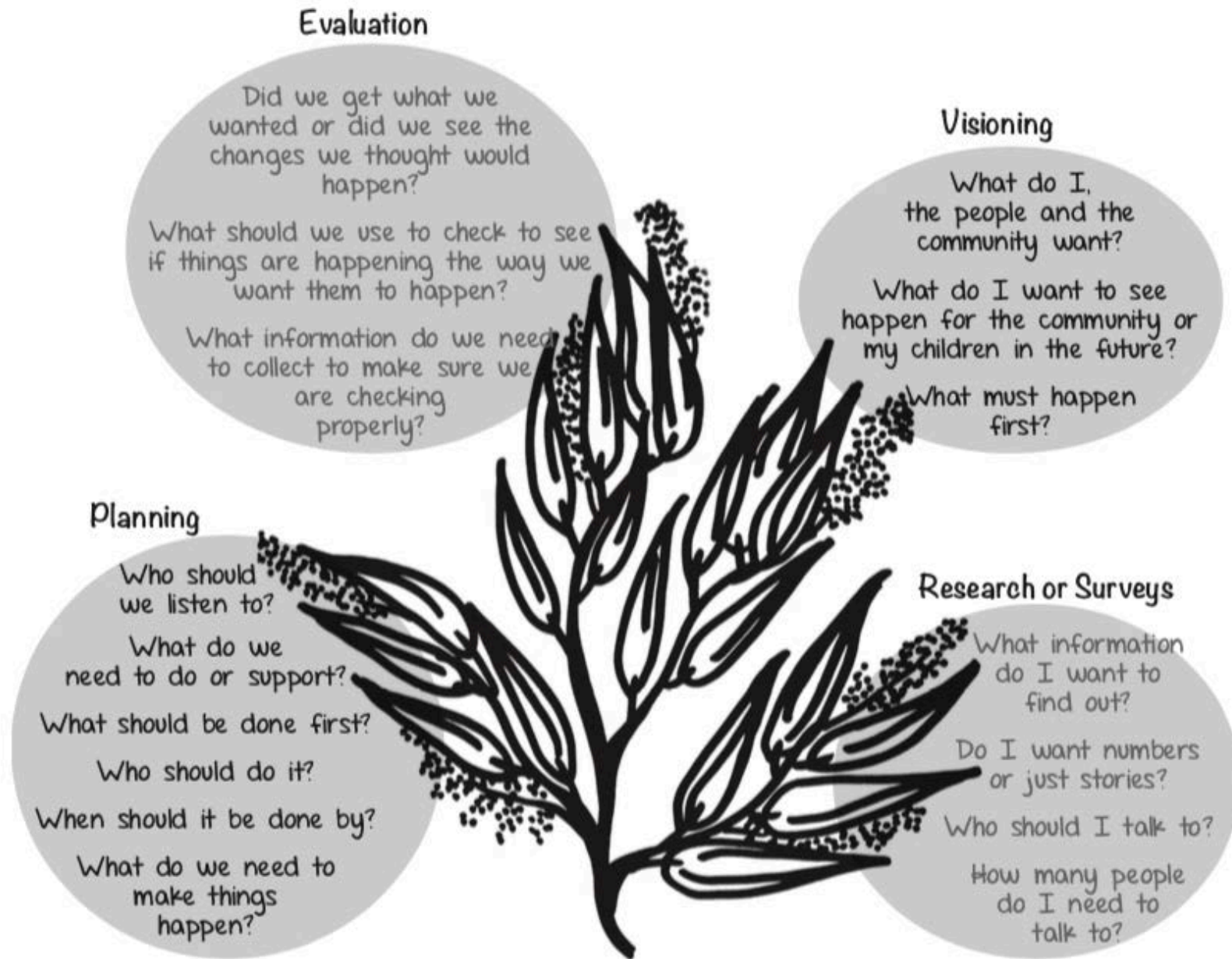


Figure 3. Types of situations where you can use the tools.

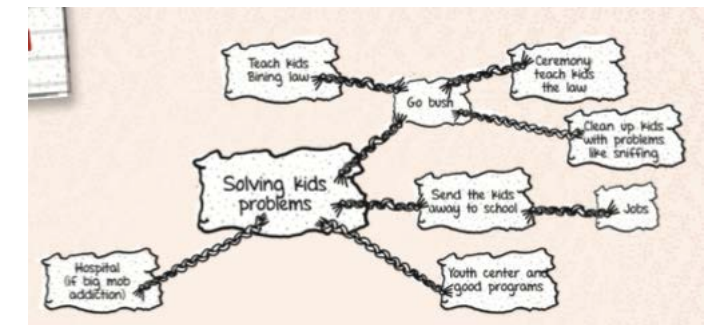
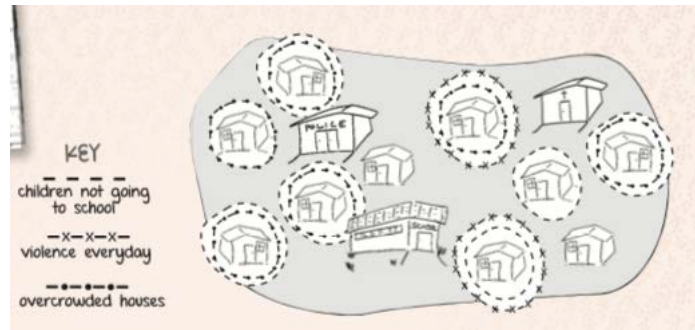
7 ARPNet Rules

1. Respect and acknowledge Traditional Owners (TOs) on the country on which you work. Make sure people are comfortable working with you.
2. Get permission from all the right people and where possible respect cultural protocols - like avoidance relationships.
3. Remember no grog, drugs, gunja or substances use while on the job. Also remember no fighting on the job.
4. Do not humbug people, if they don't want to do it, leave them alone.
5. Do not give your opinions, lock them in a box and throw away the key.
6. Start together and finish the job together. Do your best and don't give up. Work in teams or groups so you can support each other when you see one team member is struggling.
7. When on the job leave some home problems behind till job is finished. When you are on the job family can't come too, it can create problems for the group.



The dilly bag has tools for:

- Group yarns
- Interviews
- Questionnaires and Surveys
- Participatory methods
- Ranking
- Mapping
- Diagrams
- Role plays



Examples

- National Centre for Indigenous Genomics
 - <https://ncig.anu.edu.au/>



<https://www.youtube.com/watch?v=wftujBV2LPs>

Examples

- Language Research
 - Cultural knowledge and IP must be core considerations
- Research on societal problems that impact Aboriginal and Torres Strait Islander people (family violence, gambling)
 - Critical to engage early with Aboriginal and Torres Strait Islander communities and organisations so the research is designed around Indigenous ways of doing things
- Contracted research (e.g. evaluations for government)
 - Do contracted requirements benefit Aboriginal and Torres Strait Islander peoples?