When do formal ethics processes interfere with an ethical approach?



## The rationale for and benefits of formal ethics process

- Historical practices informed need for formal independent review and approval process
- The principles are right: Focus on risk and vulnerability
- The review process can add value
- Process has been improved:
  - Review process streamlined for low and negligible risk projects
  - Option to use ethics review panel with fast turnaround time

#### **Issue 1: The decision**

- Who makes the decision that formal ethics approval is needed?
- On what basis?
- What assumptions are made about vulnerability of certain population groups, by whom and how widely applied?
- Do they come to the same conclusions?
- Our experience is that the decisions are different for projects in similar content areas

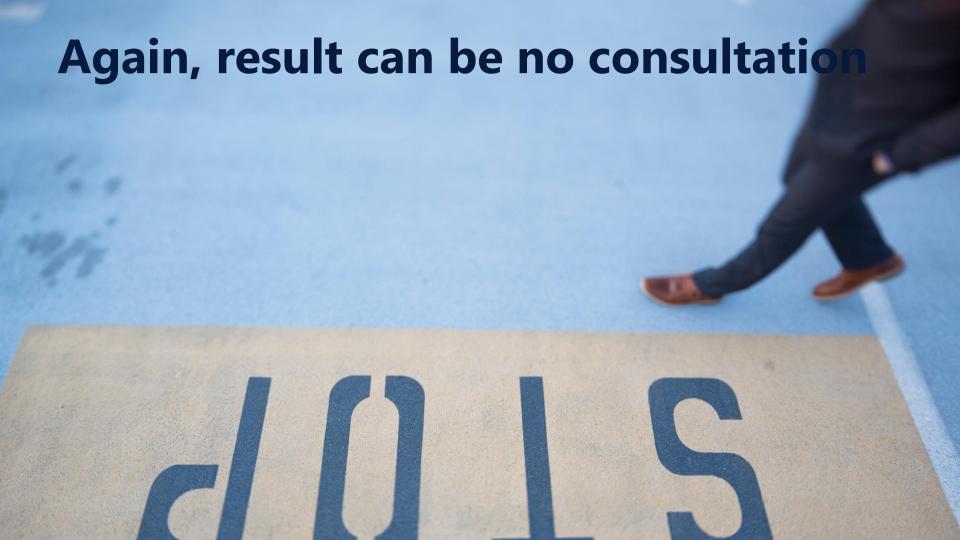
## **Issue 2: The process**

- Lengthy timeframes > delays
- There are limited options for ethical approval for research in Indigenous communities that can compound issues with timeframes
- There are costs involved in the review process and options for faster turnaround time involve additional costs
- There are different views on what is in and out of scope (e.g. ethics for consulting staff)
- Clinical research paradigm



## **Issue 3: Implementation**

- Who consents
  - Young people under 16, parental consent requirements
  - People with intellectual disability with guardians
- How you consent
  - Arms length recruitment: always appropriate?
  - Information form content requirements: overwhelming?
  - Written consent: always possible?



# Issue 4: Who has ability to own the principles in evaluation consultancy?

AHMRC principles for research with Indigenous communities

- 1. **Net Benefits for Aboriginal people and communities**: The research will advance scientific knowledge and result in a demonstrated net benefit for the health of Aboriginal people and communities.
- **2. Aboriginal Community Control of Research**: There is Aboriginal community control over all aspects of the proposed research including research design, ownership of data, data interpretation and publication of research findings.
- **3. Cultural Sensitivity**: The research will be conducted in a manner sensitive to the cultural principles of Aboriginal society and will recognise the historical aspects and impact of colonisation on Aboriginal people.
- **4. Reimbursement of costs**: Aboriginal communities and organisations will be reimbursed for all costs arising from their participation in the research process.
- **5. Enhancing Aboriginal skills and knowledge**: The project will utilise available opportunities to enhance the skills and knowledge of Aboriginal people, communities and organisations that are participating in the project.



#### Where does this lead us?

- 1. How do these issues resonate with your experience?
- 2. What other issues need to be considered?
- 3. What are some ways forward?

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