

When do formal ethics processes interfere with an ethical approach?



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ARTDCONSULTANTS

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

Result can be no consultation

STOPS



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?

Again, result can be no consultation

STOPS

A low-angle shot of a person walking on a light blue paved surface. In the foreground, a large, rectangular, light-brown cardboard sign lies flat on the ground. The sign has the word "STOPS" printed on it in large, bold, dark blue capital letters. The person, wearing dark trousers and brown shoes, is walking from right to left, their legs and feet visible in the upper right portion of the frame. The background is a blurred continuation of the paved surface.

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?



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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