



# Respecting Aboriginal Communities in Health Research

New standards for the conduct  
of health research involving  
Aboriginal people



# **A researcher and ethics board education module**

Developed by the Canadian  
Institutes of Health Research  
and the National Council on  
Ethics in Human Research



# A Tale of Two Communities

- Nuu-chah-nulth - BC
- Sandy Lake - Ontario



# Overview

- Background/Foundation for Aboriginal Involvement in Policy development
- Aboriginals' Concerns in Research
- Policy Development Strategy and Process
- New Guidelines
- Protocol and Research Process



# TriCouncil Policy Statement 1998

“... some research involving Aboriginal individuals may also involve the communities or groups to which they belong. The Agencies affirm that in developing ethical standards and practices, Aboriginal peoples have rights and interests that deserve recognition and respect by the research community.”



# Federal Position on Consultations

*Aboriginal people should have substantial involvement in the making of decisions that directly affect them.*



# Aboriginal critiques of research

- Perception of best interest of research as driver rather than Aboriginal well-being
- Research hypotheses and data interpretation often do not incorporate an Aboriginal perspective and often not consistent with community priorities and interests



# Aboriginal concerns

- Individual and group identity will not be protected
- Adequacy of protections from potential harms posed by research
- Voluntariness of participation
- Research focus on deficits and problems leads to stigmatization of individuals and communities



# Aboriginal concern for cultural integrity

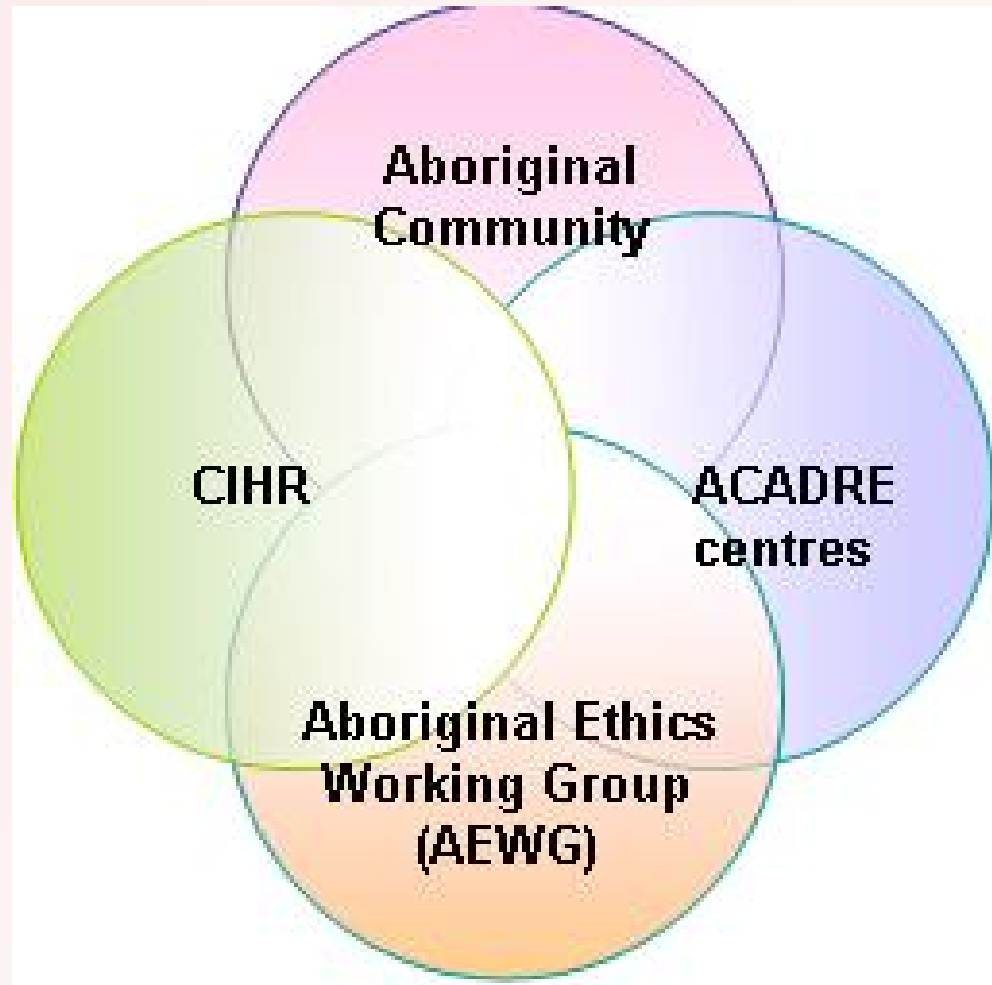
- Unauthorized dissemination and secondary use has led to conflicts and disrespects culture and tradition
- Lack of Aboriginal involvement in data and contextual analysis leads to misinterpretation
- No discussion of IP



## Results in ...

- An erosion of trust between researchers and the Aboriginal communities
- Suspicion and hostility toward research
- Reluctance of communities to participate in research that may be beneficial

# Founded on a Partnership





# Project Strategy

- “Bottom Up” process consistent with traditional values and culture
- Community and Elder Dialogues on cultural values and ethics
- Guidelines based on background and issues papers and traditional values and ethics
- Consultation process included Aboriginal, institutional and research communities
- Broad vetting with 3 communities



## **CIHR Guidelines - Formalize Relationships**

- Memorandum of Understanding to outline expectations of the community and researcher (where no relationship exists)
- Research Agreement a binding agreement covering terms of the project and issues raised (“best practices” model agreement)



# When Do Guidelines Apply?

- CIHR funded research when:
  - research hypothesis relates to Aboriginal people
  - recruitment criteria includes membership in Aboriginal community for entire study or sub-group
  - analysis of research data will use Aboriginal community membership as a variable
  - findings will refer to Aboriginal peoples, language, history or culture



# Approvals Needed

- Local community and university approval for single community projects
- Regional or national approvals and university approvals for multi-site projects
- Protocol Procedures in schematic flow chart form (A step by step process for establishing research partnerships and obtaining ethics approval)



# Community Benefit

- Research must mutually benefit the community and researchers
- Researchers should support education and training for Aboriginal peoples and communities




## Secondary Use of Data

- Respecting community jurisdiction
- Recognizing and respecting a community's proprietary interest in the collection, use, storage and potential future use of data
- Biological research samples are “on loan” to the researcher



# Cultural Appropriateness of Research

- Need to understand and respect Aboriginal world-views
- Cultural knowledge in research should be under mutually agreed terms and with the guidance of community knowledge holders
- Need to learn about and apply Aboriginal cultural protocols relevant to the particular Aboriginal community
- Translation of publications or reports into the language of the community



# Cultural Appropriateness of Research (2)

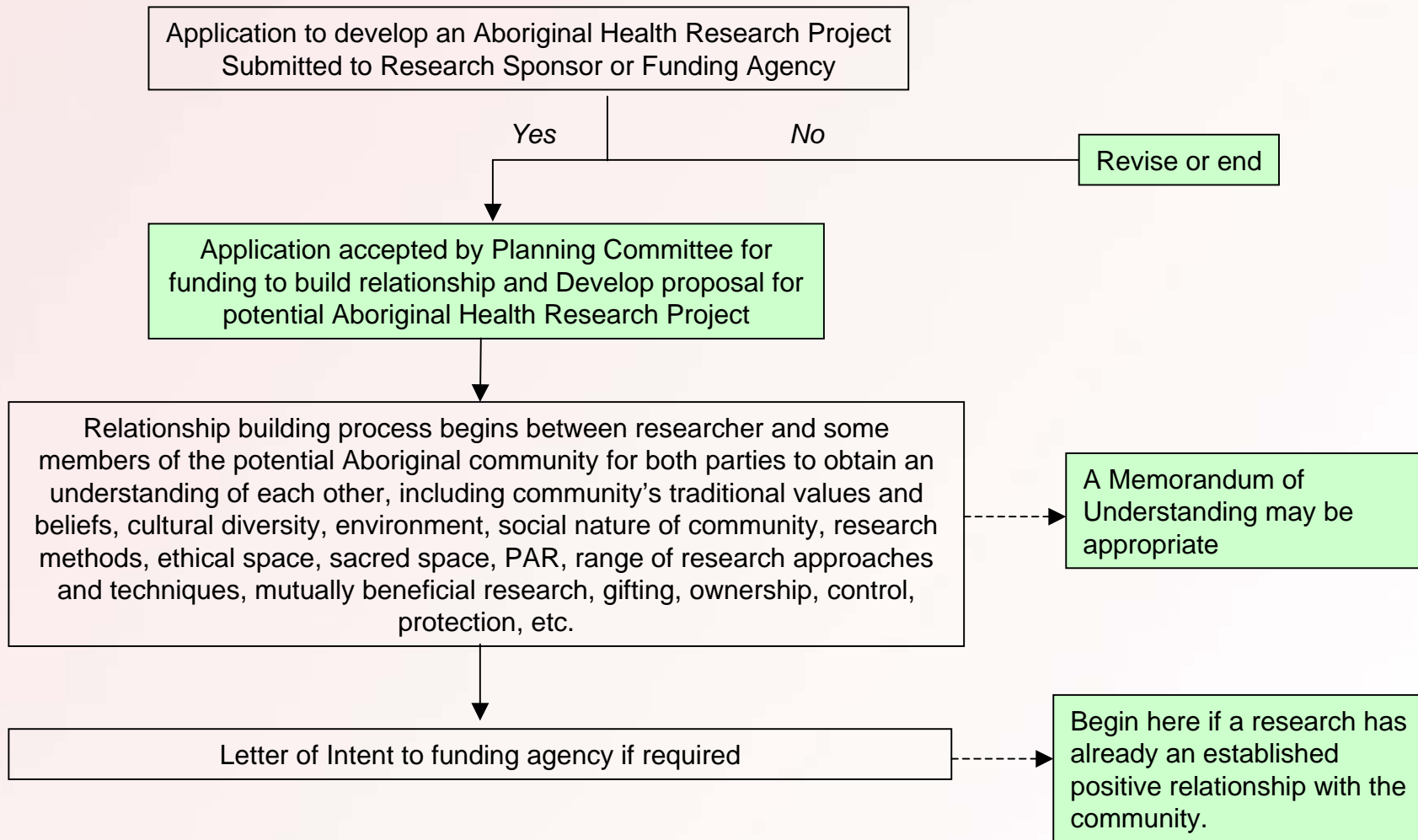
- Ensure an effective on-going communication that is accessible and understandable to the community
- Aboriginal communities should have an opportunity to participate in the interpretation of data and/or review of conclusions drawn from the research



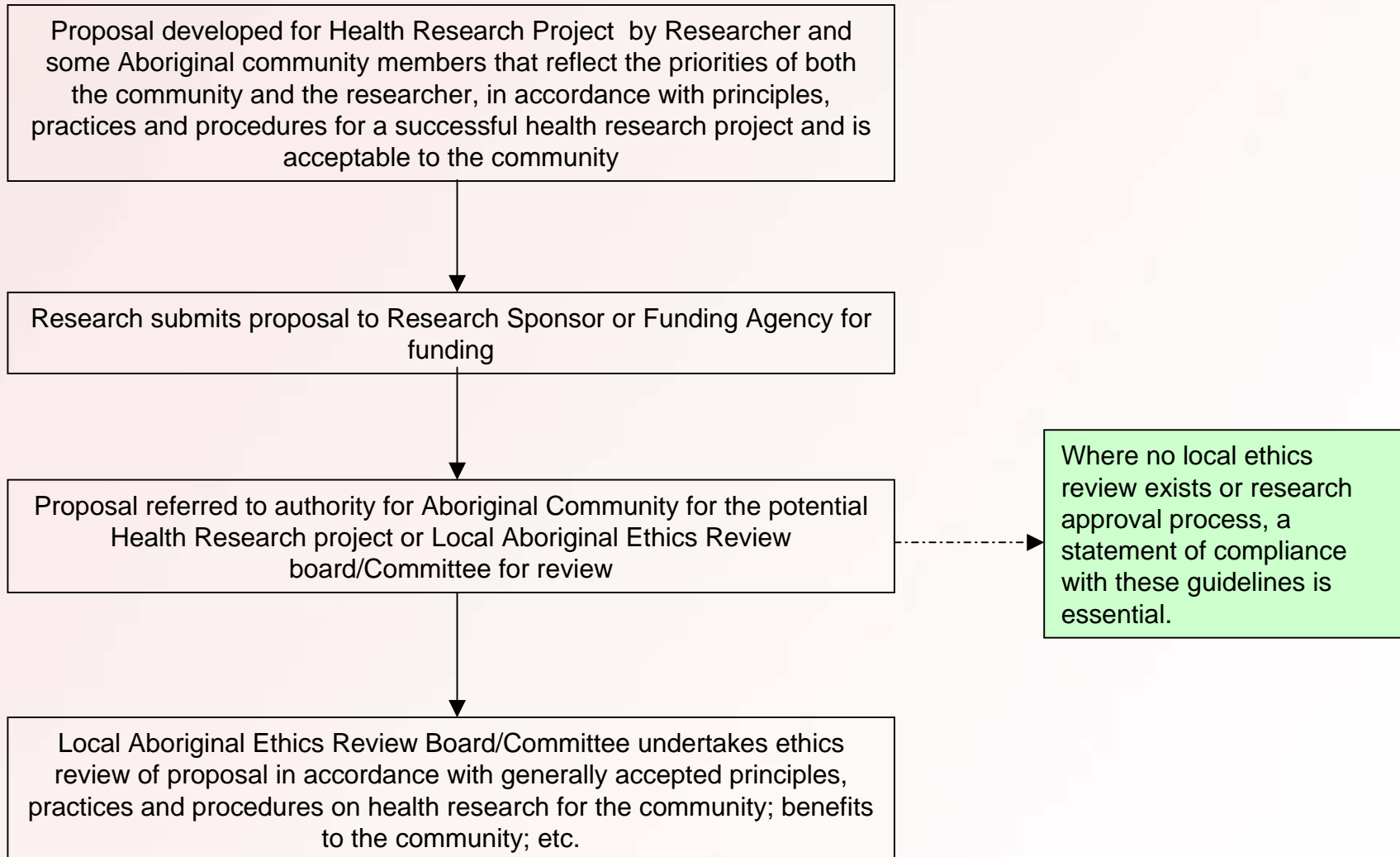
# Jurisdiction and Partnership

- Community control over the conduct of research should be understood and respected
- Communities should be given the option of a participatory research approach
- Indigenous concerns over intellectual property should be explicitly acknowledged and addressed in a research agreement

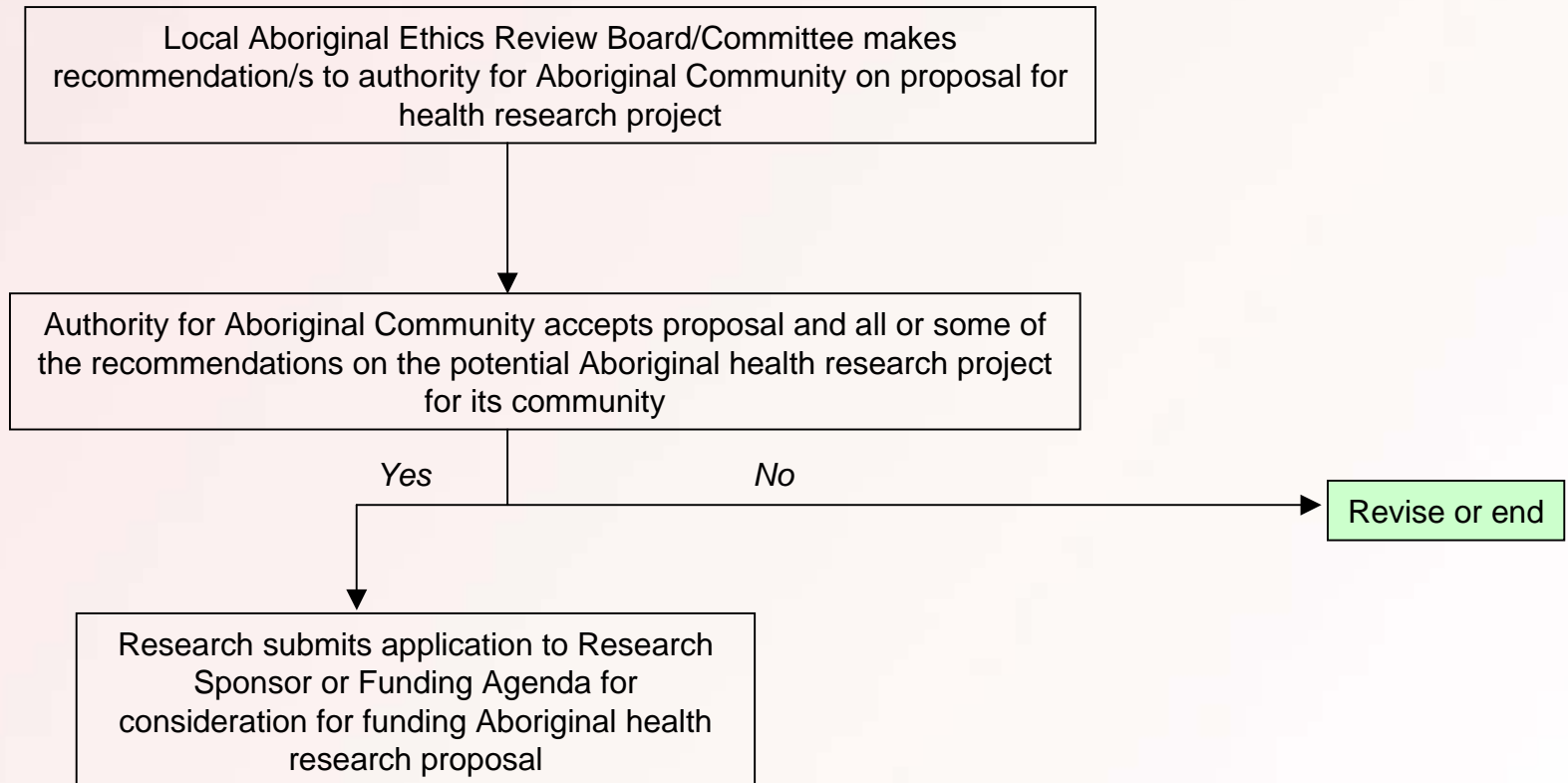
# Step 1: Partnership Development



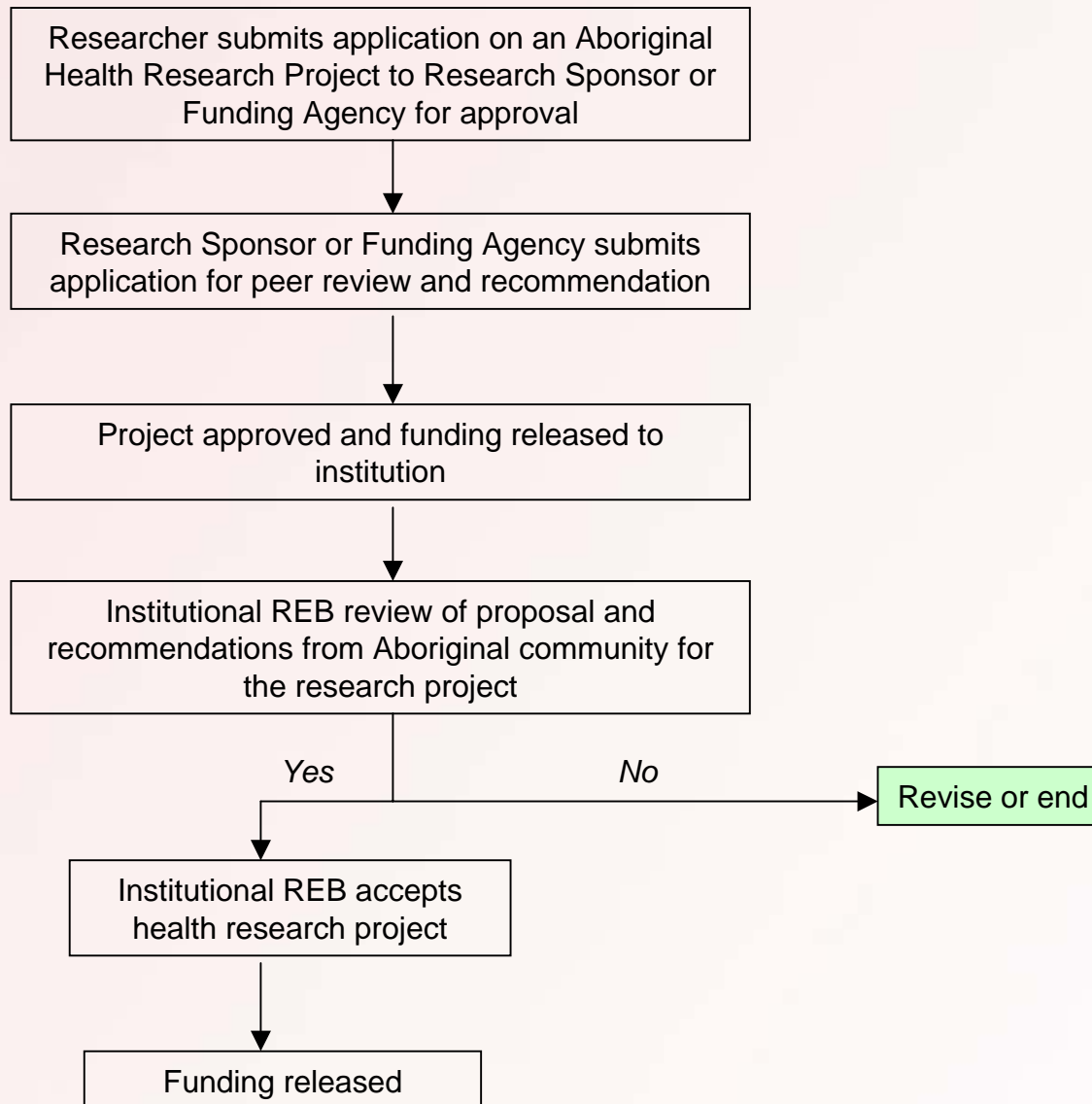
## Step 1: Partnership Development (cont'd)



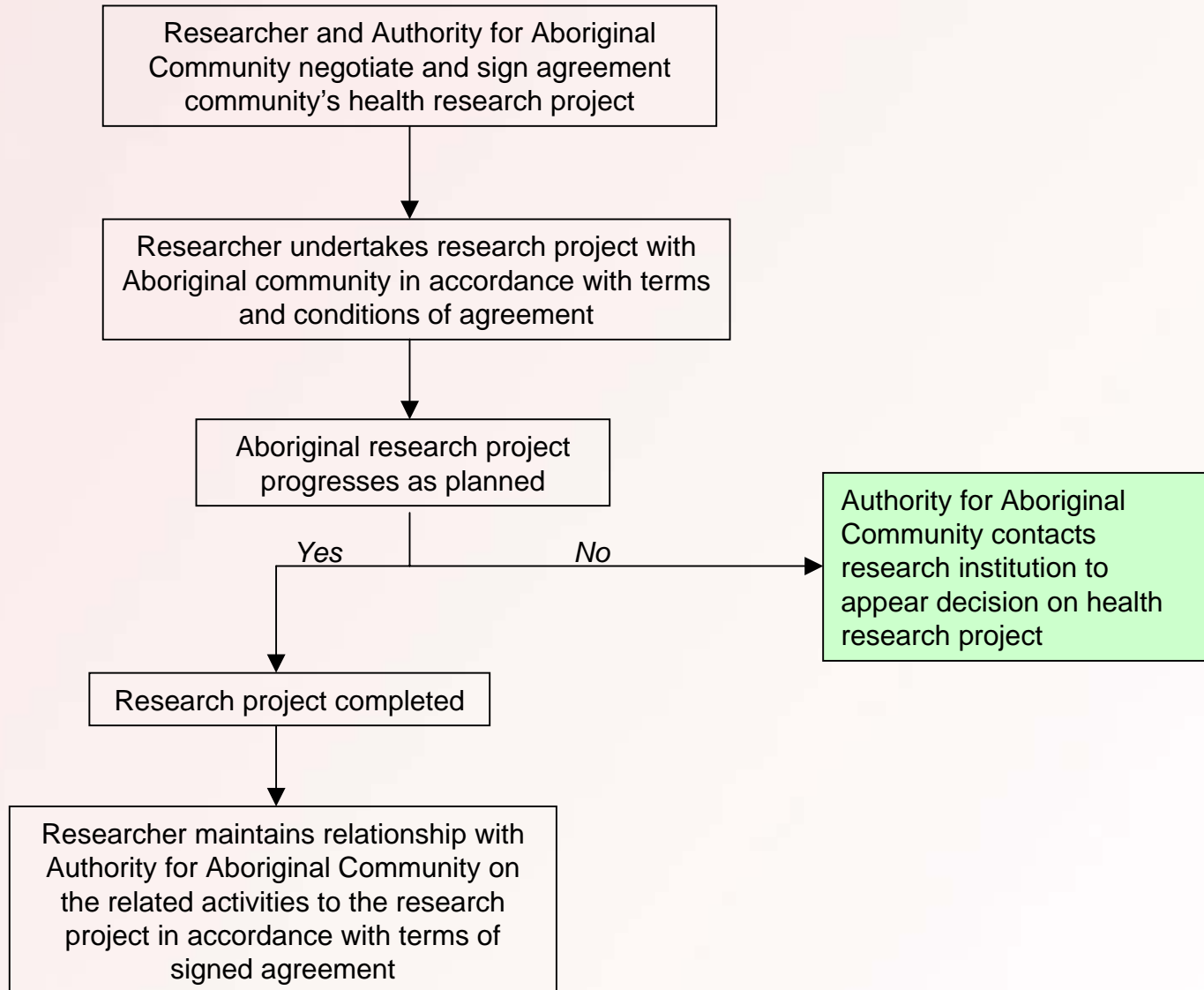
## Step 1: Partnership Development (cont'd)



## Step 2: Submitting Proposal



### Step 3: Maintaining the Relationship





# Policy Implications

- Researcher and institutional compliance will be required for grants and awards
- REB will need to make a determination of appropriate community involvement
- May require additional time for relationship building – lengthening process



# Policy Implications

- Establishing partnerships means working with communities before REB approval
- Peer reviewers and REBs need to better understand community-based research
- More direct involvement in education of researchers