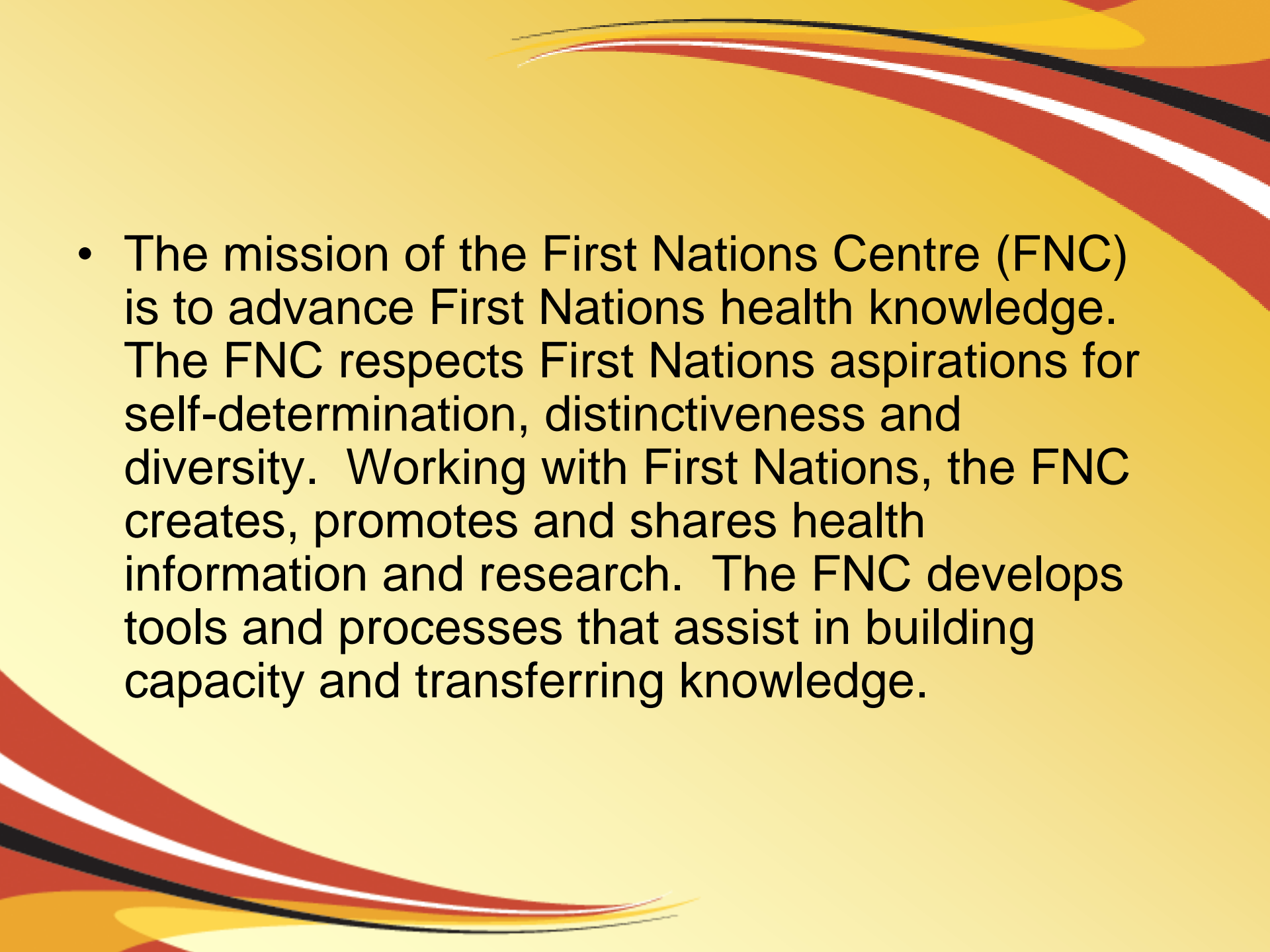


# First Nations Centre



**OCAP and Research Ethics in First Nations Communities**

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- The mission of the First Nations Centre (FNC) is to advance First Nations health knowledge. The FNC respects First Nations aspirations for self-determination, distinctiveness and diversity. Working with First Nations, the FNC creates, promotes and shares health information and research. The FNC develops tools and processes that assist in building capacity and transferring knowledge.

## **Empowering First Nations**

The First Nations Center uses knowledge-based strategies to assist First Nations individuals, communities and leaders in making effective and appropriate health choices.

## **Self-Determination in Health Information for First Nations**

The First Nations Centre raises awareness of, and acts in accordance with, First Nations ownership, control, access and possession (OCAP) of their information for purposes of planning, accountability, advocacy and health care.

## **Relationships with First Nations**

The First Nations Centre builds and enhances ongoing relationships with First Nations individuals, communities, and organizations.

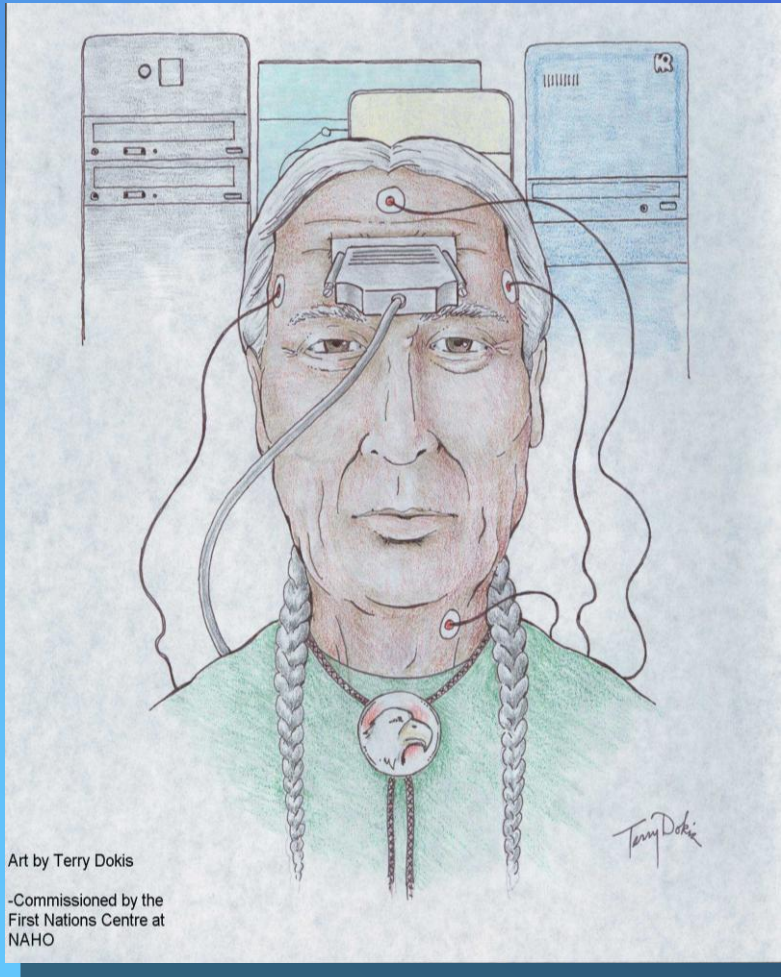
## **Relevance to First Nations**

The First Nations Centre aims for its activities to benefit and make sense to community leaders, health workers, and members

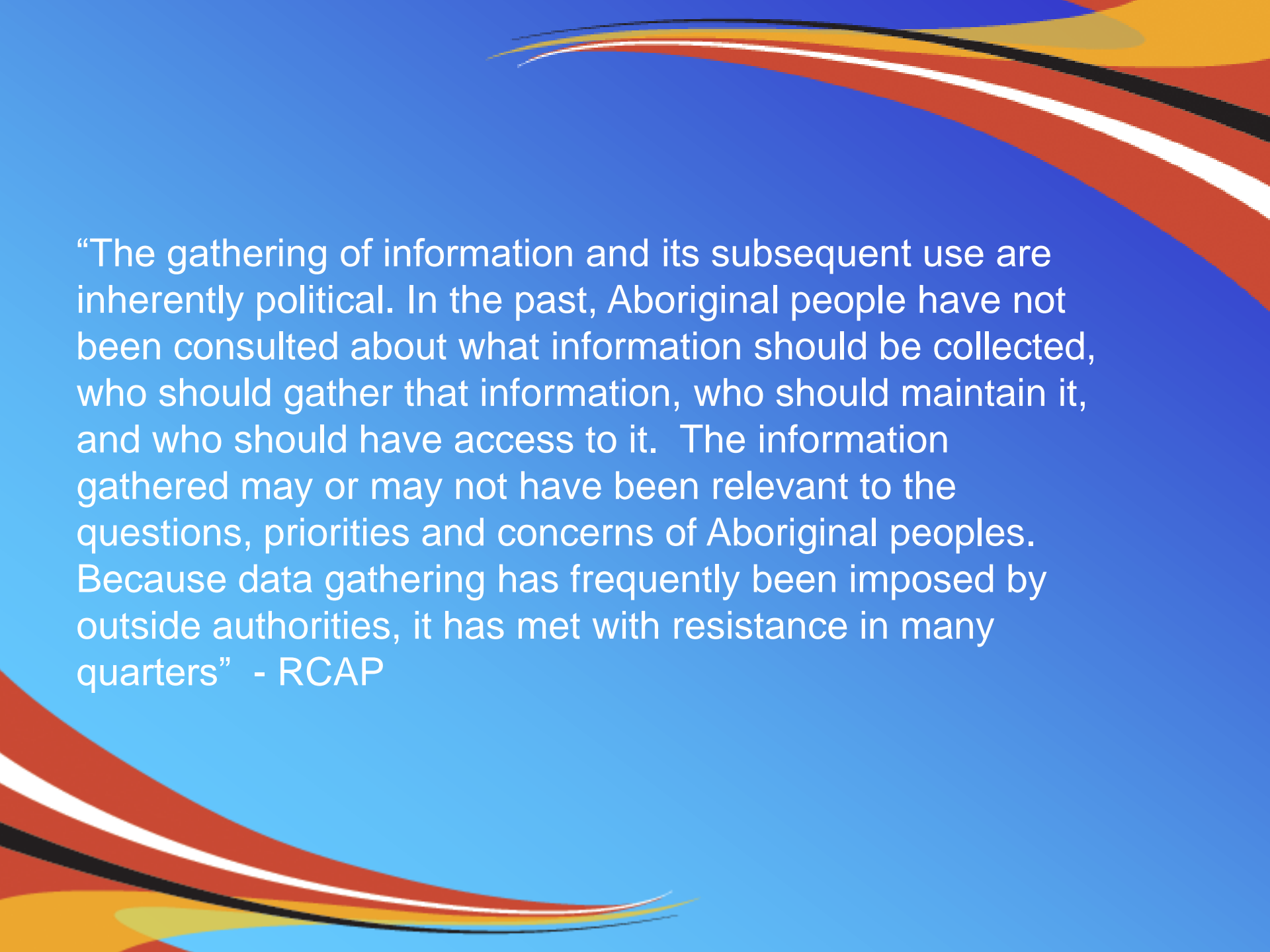


# OCAP

**Ownership, Control, Access and Possession**



- In the past, it was common to hear the phrase “We have been researched to death”.
- The focus has now changed. In the present we can now say, “We are researching ourselves back to life.”



“The gathering of information and its subsequent use are inherently political. In the past, Aboriginal people have not been consulted about what information should be collected, who should gather that information, who should maintain it, and who should have access to it. The information gathered may or may not have been relevant to the questions, priorities and concerns of Aboriginal peoples. Because data gathering has frequently been imposed by outside authorities, it has met with resistance in many quarters” - RCAP

## Ownership

- Relationship of FN community to its cultural knowledge/data/information
- Community/group owns information collectively, as individuals own personal information
- Distinct from possession

## Control

- FN aspirations & rights to maintain, regain control in all areas of their lives includes research, data
- Control should cover all stages of a research project
- Control can extend to resources, policy, review processes, formulation of conceptual frameworks, data management etc.

## Access

- FN's must have access to information, data about themselves and their communities, wherever it is held.
- FN communities and organizations have right to manage and make decisions regarding access to their collective information.

## Possession

- Possession (stewardship) is a mechanism to assert, protect ownership.
- When FN data is in the possession of others (e.g. government, academia), there is a risk of breach or misuse. Especially when trust is lacking between owner and possessor.

## What does OCAP mean for First Nations health research and information?

With respect to health research that is proposed or initiated by an external partner, there are steps that your community can take to ensure that OCAP principles are respected. These include:

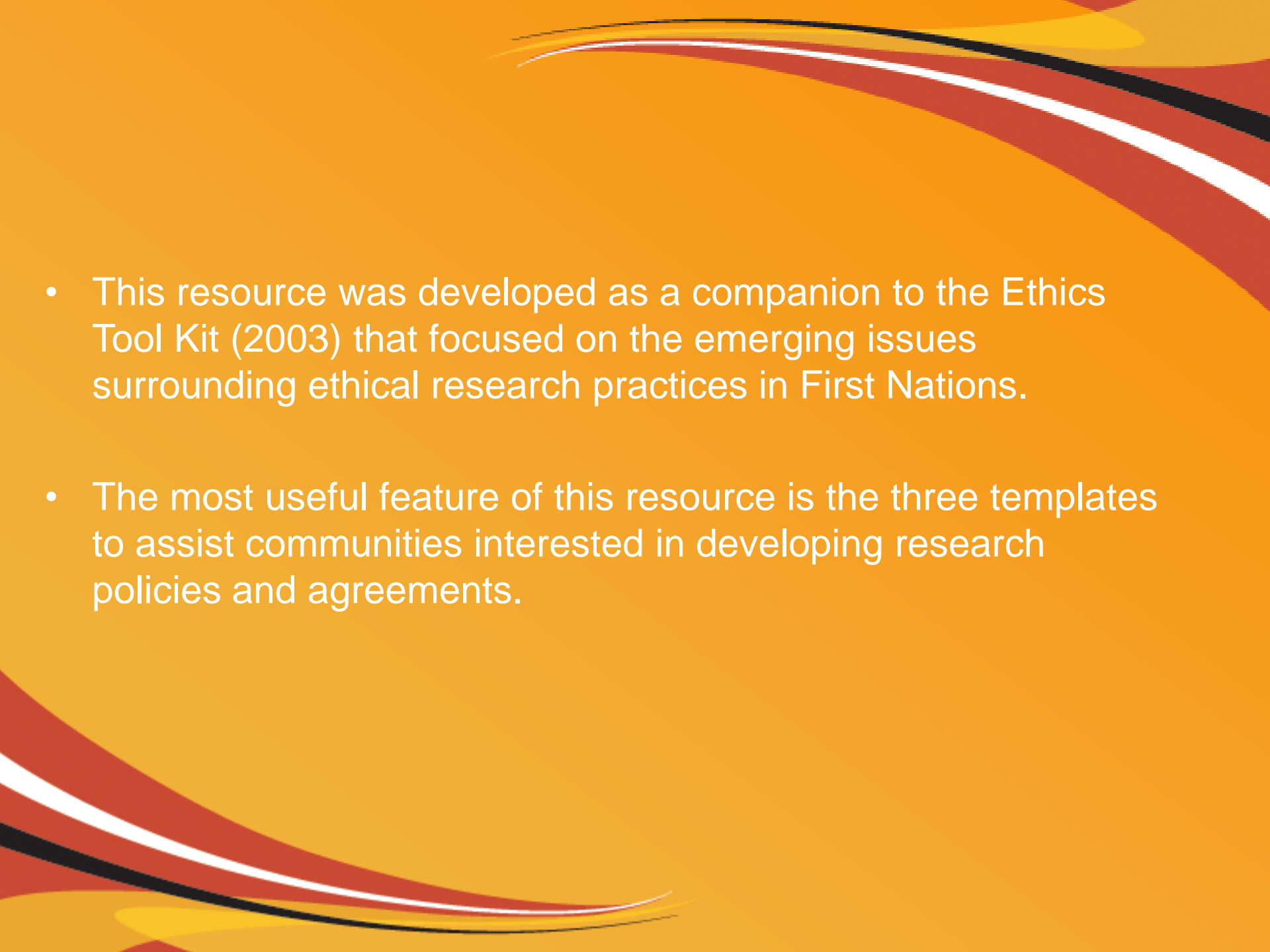
- Establish a research committee in your community to ensure careful and consistent consideration of all proposed research activities;
- Identify community priorities for health research and choose to participate only in projects that are relevant to these issues;
- Develop criteria for reviewing research proposals;
- Develop a community code of research ethics, or a code of conduct for external researchers; and,
- Insist on meaningful participation in all aspects of community-based research.

# BENEFITS TO OCAP

- Helps rebuild community trust in research.
- Improves quality and accuracy; people invest more effort when information is perceived as valuable.
- More democratic (participatory) methods.
- Higher participation rates.
- Encourages more holistic (FN) approach to health.



**Considerations and Templates for  
Ethical Research Practices**

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- This resource was developed as a companion to the Ethics Tool Kit (2003) that focused on the emerging issues surrounding ethical research practices in First Nations.
  - The most useful feature of this resource is the three templates to assist communities interested in developing research policies and agreements.

# Template for a Code of Research Ethics

- This model contains useful policies and procedures that need to be considered in governing, managing or guiding research activity in First Nations.
- Is a framework of principles and procedures to regulate and guide all research in a community.
- Has many benefits such as increasing public awareness of First Nations' policies, principles, protocols, and rights in relation to research. Its very existence serves as a foundation to assert self-determination over research in the community (i.e, assertion of OCAP).
- Useful in reviewing proposals, managing research partnerships, overseeing research and researchers and monitoring, evaluating and reporting on the code's implementation and use.

# Template for a Collaborative Research Agreement

- A collaborative research agreement represents a formal summary of rights, responsibilities and expectations between the research parties. Information regarding the principal researchers and the research project is usually included in the agreement.
- It ensures that the research process is transparent, that interests are appropriately balanced, and that all parties understand and agree on a range of issues.
- This ensures an equal research partnership.

# Template for a Data-Sharing Protocol

- Is a formal agreement between the community and the research partner(s) which summarizes the conditions and arrangements for sharing the community's information or data.
- The agreement sets out the fundamental principles and obligations that the research partners must adhere to when they collect, use, store and disclose individual or aggregate data.
- This is a useful tool in protecting individual and community interests, information and privacy.