

# **DELINE GUIDELINES FOR RESEARCH**

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***Dene Gok'aréhkw'ı Kə Godı Kə Erjht'ə Weʔo***

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## Introduction

*This guidebook is dedicated to the present and future children of Deline.*

In the year 2000, Deline launched a major three year program to research the human and environmental impacts of Port Radium. This program was established through the formation of the Canada Deline Uranium Table. As part of this program, Deline identified a way of working with researchers to ensure a level of community control and participation in research.

Now, as we near the end of the program, it is time to evaluate this experience and to develop a set of research guidelines for future use. As well, guidelines are needed to ensure that the community will benefit from the results of research activities, and that community knowledge is protected.

In September 2003, a series of four focus groups held with elder and adult women and men identified the need for a committee to draft the research guidelines. Representatives were selected from the focus groups to form the committee. The committee called itself Dene Gok'aréhkw'I Kə Godı Kə Erıhtı'á Weřo.

We now present this draft document to the community for review and approval. We welcome your input. This is intended as a living document, to be reviewed and revised as needed.

### **Our Purpose**

- To develop respectful community guidelines for research.
- To develop a respectful way to do research and reporting.

## **What is research?**

Research is the ongoing collection, analysis, and interpretation of information. People gather and document information in many different ways, including interviews with people about what they know, or various kinds of scientific testing including testing on animals or plants. Most organisations and governments keep records that are important sources of information about the past.

The goal of research is to gain new insights and knowledge. Researchers decide to use certain methods to collect and interpret information depending on the purpose of project. Often research is done in a very systematic way, with the aim of making a new discovery. Sometimes the purpose is artistic, educational, political, or ethical.

Once this knowledge is gathered, it is given back to the people and communities in various formats, including reports, films, newspapers, and art works. The decisions about how research should be shared needs to take into account privacy issues and respect those involved in the research.

## **Our Past Experience**

The historical experience of Deline in the area of research has in many ways been very negative. Research programs and projects affecting the people and their traditional lands have been designed and implemented by outsiders without community control or participation. The exclusion of community members has been linked to a weakening leadership capacity, along with a loss of traditional knowledge in the community.

### **The Colonial Legacy**

Deline is still affected by the legacy of colonialism, when Dene people lost control over their traditional lands. Colonialism refers to the time when white people took over. European laws were imposed on the land and people, so Dene people could no longer apply their own laws. Dene knowledge was pushed aside by foreign knowledge systems enforced by the government, church and residential schools.

### **Research By Outsiders**

For the most part, research in the Deline District has been imposed from the outside, without community consultation. People often did not have the capacity to understand what researchers were doing or why. Researchers would use the research results for their own benefit and the community rarely even received final reports. In any case, reports were usually written for outsiders in a format that was difficult to understand.

### **Rights and Capacity**

The Sahtu Dene and Metis Land Claim Agreement (1993) has restored to the people of Deline the right to participate in many processes affecting their lives. But there has been little leadership development and capacity building to ensure that these rights can be exercised successfully.

## Other Research Guidelines

It is useful to be aware that outside researchers are required to adhere to other guidelines established by their universities, their funders, or the Aurora Research Institute – the body that issues licences for all research in the NWT.

At a federal level, the most influential guidelines are those developed by the three councils that fund research in natural sciences and engineering, social sciences, and health. The *Tri-Council Policy Statement* includes guidelines for consent, privacy and confidentiality, and special considerations for research involving aboriginal people. However, these guidelines are mainly relevant to conventional scientific research activities. They are oriented to protecting researchers and their universities and funders – participant community or individual needs are not necessarily addressed.

The Aurora Research Institute uses the licensing process to ensure that researchers “understand and respect” the special conditions of northern research. Researchers must obtain formal support from participant community councils as a condition of being licensed. Beyond this, the level of accountability to the community is minimal.

In the past, the people of Deline had a strong Dene law and spirituality to guide them. They did not need written policies; rather they relied on the respect and trust that comes when people work closely together. Now that Dene people have begun working closely with outsiders, it has become necessary to develop a strong written framework for research that embodies our values. This will ensure that outside researchers are held accountable, and that research fits community priorities.

Most importantly, research must benefit the people of Deline and their traditional land base. Researchers should respect Deline’s strategy for strengthening traditional culture and practices, and building a healthy community and environment.

## **The Deline Uranium Team Experience**

The story of the Deline Uranium Team is the story of the biggest research program ever undertaken in the community. This program was the outgrowth of community questions about the impacts of the Port Radium mine. To answer the community's questions the Canada-Deline Uranium Table was formed, which has been a key national example of collaborative work undertaken between the Government of Canada and an aboriginal community. In order to answer all the questions a three year Action Plan was developed and implemented through collaboration between the community, the Federal Government, in particular the Department of Indian and Northern Affairs and outside specialists. Over the past few years, we have learned much about how we can work together in a respectful way.

### **Defining the Research Questions and Methods**

The community began by developing a list of goals related to the uranium issue, known as the Fourteen Points. In negotiation with the Federal government, it was agreed that a research program to identify impacts was required before progress could be made. Community members came up with a list of seventy-seven questions that they wanted to have answered.

The next step was a community workshop with a panel of specialists to decide what kinds of research methods and expertise were needed to answer the questions. This discussion gave rise to an Action Plan that everyone agreed to. The Action Plan defined research programs in the areas of health, environment, and traditional knowledge. The linkages among the three programs were also outlined. Overall decision-making on all projects rests with the Deline Dene Band.

Although specialists would be required to lead the research, the Action Plan affirmed that community participation through communication, education and capacity building should be planned as important aspects of each research project. Community participation has varied from project to project. Community workshops, presentations at public meetings, and a newsletter series have all served to build awareness of the activities and to invite feedback.

## **Environmental Science**

The first specialist hired to live and work in the community was an environmental scientist. A contracting company was selected to conduct site testing, and Deline people were hired and trained to provide technical assistance in the testing program. A training program in Environmental Monitoring was begun in the community.

Project results were presented at community workshops. The community found that it was difficult for scientists to explain their work in a way that everyone could understand. The fieldworker team was then asked to work with specialists to develop community presentations in the Dene language.

## **Health**

The health program was initially managed by a specialist not living in the community. This made it difficult for the people of Deline to feel that they could have a strong voice in how the program should be implemented. The program gained momentum when a specialist was hired to live in the community. Focus groups with women and men of the different age groups were held to evaluate progress to date and provide guidance on future work.

Most of the health research involved specialized work with individuals and a high level of confidentiality. Community members were hired mainly as interpreters, and they had to swear a confidentiality oath.



## **Traditional Knowledge**

From the beginning, people understood the importance of documenting their knowledge, and that community people were the best people to do this work. But the particular skills required to conduct the research were not recognized until the second year of the Action Plan. A specialist was hired to live in Deline and assist in training a community research team. The program was designed following the Participatory Action Research model.

The researchers called themselves Dene Náowéré Chets'ele, and termed their research method ?ehkw'1 Gots'eruchu Gha Ełehá Eghálats'eda/Working Together to Go the Right Way. The team assisted in the design of the research, facilitated focus groups, and conducted interviews. Community members were also invited to assist with guideline development, project design and verification through community workshops and focus groups.

The high level of participation led to a noticeable increase in the level of active support for the research over the two years. This support also had a positive effect on other projects, since the traditional knowledge researchers assisted in presenting all Action Plan activities to the community. The team was able to show how the health and environmental projects relate to traditional knowledge.

## **Dene Náowéré Chets'ele**

The Deline Uranium Team's community researchers benefited from the long Northern research experience of their first trainer, Joan Ryan. Dr. Ryan worked with community staff to adapt the education program to the specific requirements of our Action Plan.

The projects required an understanding of traditional knowledge and scientific research. The complexity of the projects made it necessary to learn through experience, as well as formal academic training. A partnership was built with Aurora College to provide upgrading in computers, English, and math.

The community researchers developed skills in traditional knowledge research by participating in the design and implementation of the research. They learned research design methods, use of recording equipment, and interviewing techniques. Dene language training was an ongoing part of the program, including knowledge translation, interpreting, writing in the language, and transcribing oral histories. The researchers became more fluent in their language in using Dene language as their language of work.

The training involved team-building, and the community researchers developed a culture of supporting each other in their work. They also developed capacities as communicators and community leaders in promoting Dene language use and traditional cultural activities.

## **The Importance of Dene Language**

One of Deline's strengths is that the majority of community members continue to speak Dene language as their first language. Actively speaking the language has helped the community to maintain their traditional knowledge and values. This is important for outside researchers to recognize.

Community members recognize that if they actively use and maintain their language, their children will be proud of their heritage and their culture will be kept alive. The community is making a great effort to recognise and encourage the use of Dene language. Outside researchers are asked to respect this effort and engage translators whenever possible, as well as ensure that any written material or public presentations are made available in English as well as the Deline dialect of the Dene language.

It should also be recognized that translation is a cross-cultural process. Direct translations from one language are not always possible. In bringing together traditional knowledge and scientific research, it will often be necessary to budget time for language development work with a collective including elder representation. This also applies to project reporting in the community.

## **A Vision for the Future**

Deline has a vision for developing a model research community in which people work together and share knowledge to benefit everyone and shape the future.

## **Our Strengths**

As a community we possess important strengths that will help us to achieve our vision. Our people still have their traditional skills for surviving on the land. We have our stories that contain much valuable information. And we are still strong in our language.

## **Principles**

Principles are the values that guide our work together. The following six principles underpin the community vision for research:

- Dene people participate in all aspects of research.
- Research is conducted according to Dene values and guidelines.
- People are made aware of how research will benefit them.
- Volunteer participation is encouraged.
- Dene knowledge is used as a resource in all research.
- Dene language is used as a starting point for research.

## **Achieving the Vision**

Our guidelines for research are *strategic* in that they identify priority areas for change and development.

### **Our Goals**

In analysing the changes required to achieve our vision for research, we have identified four goals to be worked on in the community:

1. Reclaiming our heritage
2. Full participation
3. Building capacity
4. Sharing research results

## **Goal 1: Reclaiming Our Heritage**

The report of the Traditional Knowledge Working Group (1991) defines Traditional Knowledge as follows:

Traditional knowledge is knowledge that derives from, or is rooted in the traditional way of life of aboriginal people. Traditional knowledge is the accumulated knowledge and understanding of the human place in relation to the universe. This encompasses spiritual relationships, relationships with the natural environment and the use of natural resources, relationships between people, and is reflected in language, social organization, values, institutions and laws.

“Local knowledge” is a term that is sometimes used to refer to the knowledge of Dene people. But this does not capture the historical and cultural aspects of Dene knowledge.

Dene people possess a unique body of knowledge that has accumulated through generations lived on the land; it should be valued equally to other knowledge systems. For example, Dene knowledge is important in monitoring the changing environment.

It is urgent that the knowledge of Dene elders be documented and properly understood before we lose them. Dene people should play the leading role in collecting this knowledge. Dene knowledge also needs to be brought to life in practice, through activities in town and on the land.

In researching Dene knowledge, we have to respect the land and people. Our knowledge is not for sale – selling our heritage will lead to disaster.

## **Goal 2: Full Participation**

Through the experience of the uranium issue Action Plan, Deline has developed a participatory method of research that we call ʔehkw'ı Gots'eruchu Gha Ełehó Eghálats'eda/Working Together to Go the Right Way. This approach involves the community at every stage of the research cycle, including setting priorities; developing research questions; determining how research will be done; implementation; and reporting and information sharing.

In the past, the scope of community involvement was very narrow. Researchers approached the community with a preset agenda. Dene people were recruited primarily as translators, guides, technical assistants, or informants. Research results were rarely returned to the community in a plain language form that could be understood and used by the community.

More recently, the scope of participation has expanded, taking a variety of forms. An Advisory Committee has been established to ensure that community needs are being met. Community members have been employed in a training capacity as researchers. Others are invited to provide input into various phases of research through household visits, community workshops, public meetings, and focus groups. Research teams may use more than one approach to ensure the broadest possible participation. The extent of participation and the kinds of participatory tools used are also dependent on the nature of the project.

### **Goal 3: Building Capacity**

Capacity building efforts will enhance our ability to participate in research and to get research results that meet community needs. In part, capacity building is linked to the building of a healthy community, strong in its culture and language. At the same time, we need people trained in translation, so that we can access other knowledges. Deline should build a library, and ensure that we have the ability to use it as a community resource.

Research projects should be designed with a capacity-building dimension. A priority focus for capacity building should be with the youth. Young people are caught between the traditional and modern worlds. Our Dene knowledge needs to be documented in a way that will benefit the youth, and our elders should be restored to their role as teachers. The youth need opportunities to practice traditional skills, especially through experiences on the land.

It is important to encourage people to actively volunteer in support of activities that benefit the community. At the same time, we need to ensure that funding is made available so that community goals can be realized.



## **Goal 4: Sharing Research Results**

In the past, the community did not keep or benefit from the results of research. Creative participatory approaches are needed to ensure that people understand research results and can use them. As well, the community needs to be involved in determining how their information will be shared with the outside world.

The community will balance the need to protect sensitive information with the benefits of sharing it in determining the conditions of consent. There should be community involvement in developing consent forms as required for each project in order for people to fully understand and support the terms of consent.

A committee should be struck for each research program to assist in the development of community reporting procedures. This committee needs to be empowered to make recommendations to the Chief and Band Council.

## **Strategic Evaluation**

We face a number of challenges in achieving our vision and goals for research in Deline. We need a strong leadership to promote research, and a policy to guide research activities. We also must begin to listen to our elders and recognise the importance of our traditional values and beliefs in research activities.

We are lacking in funding. People have come to expect payment for all participation, which can make full participation impossible to achieve. At the same time people are poor and unemployed, so they can't always afford to volunteer their efforts. Community members do not have the training needed to play an equal role in research. Training to build capacity is therefore an important aspect of any research program.

We have lost our sense of identity, and our voices in decision-making are thus too quiet to be heard. Our youth are losing interest both in school and in their own culture, and at times end up in jail. Yet we also know that if our youth are given the opportunity they will listen and learn from others.

We need to address each of these challenges head-on through a series of strategic community initiatives. We see the following as priorities for the community:

1. Establish the Deline Knowledge Centre, with staff and program funding.
2. Create a strong research plan to set priorities, and ensure that meetings are action oriented, toward achieving community objectives.
3. Establish a Research Committee to review research proposals and make recommendations to the Chief and Band Council.
4. Ensure that each research project is guided by an Advisory Committee with strong elder representation.
5. Develop a program for encouraging volunteers, including showing appreciation for their contributions.
6. Develop a training program in Dene knowledge and language.
7. Find ways to strengthen the role of elders in the school.
8. Establish a bush camp for at-risk youth.
9. Promote more cultural activities in town and in the bush.

## Research Proposals

The guidelines provided in this book describe some of the values and ideas the community of Deline have about possible research projects. It is important to know that each research project will be looked at in detail, and decisions will be made by the community of Deline after extensive discussions.

This makes it very important that research proposals are written in plain language and are very detailed. It is highly recommended that researchers develop their proposal together with community members and/or organizations rather than in isolation. This will ensure an early start of a collaborative partnership that reflects the needs and values of the community.

Each research proposal must include information letters for the community and consent forms that are easily understood. It is recommended that both the information letter and consent form be translated, as many people in the community speak Dene language as their first language.

An Advisory Committee will be identified to guide the work of each new research project. Depending on the nature of the project, the membership of the Advisory Committee may be drawn from an existing organisation (such as the Renewable Resources Council). The membership may also vary, but it is recommended that each committee include elder and youth representation.

The role of the Advisory Committee is to facilitate community contact for the researcher and to ensure that the researcher understands the community's values and ideas about research. If at all possible, community members with an interest or training in the researcher's field of interest will be selected to sit on the committee.

## Deline Research Proposal Form

*This form is supplementary to university, Federal and Northwest Territories ethical guidelines procedures. Completion of this proposal is a step in determining community support for a proposed research project affecting the community of Deline and the lands of the Deline District. The researcher must provide information in plain language. This will assist the Deline Research Committee to evaluate the project and make an informed recommendation to the Deline Dene Band Council. By establishing a community contact early on, we can make sure that the project fits community priorities, needs, and guidelines.*

Name		Community Contact	
Department		Mailing Address	
Institution			
Phone		Fax	
Email		Website	

Please answer the following questions about your proposed research. Responses to relevant questions should be developed in consultation with your community contact.

1. Summarize your proposed research in plain language.
2. What method do you propose to use in your research?
  - a. How will information be collected?
  - b. What will be the approach to dealing with language translation challenges?
3. How will you provide opportunities for community input and participation?
4. What capacity-building activities will be included in the project?
5. What kind of tools do you plan to use in communicating research results with the community?
6. What will be the benefits of undertaking this research?
7. What will the risks be of undertaking this research?
8. What are the local resources you are planning to use?

### Attachments

Please attach the following items:

- Your funding proposal
- A draft information letter about the project (see the outline in this guidebook)
- Resumes of the outside people involved in the research

## Sample Information Letter (Health Research)

*This information letter is an example of a way to inform community members about the research project. The information letter must include the following information:*

- *Contact information of the researcher and the people from Deline who are part of the Advisory Committee*
- *The purpose of the research project*
- *The length of time community members will be involved*
- *The harms and benefits that may come from participating in this project*
- *Affirmation that people are free not to participate*
- *What will be done with the information collected*

**Project Title:**

**Name of Lead Researcher:**

**List of Advisory Committee Members:**

We invite you to take part in a research study. The purpose of this study is to explore the health impacts of having lived and/or worked at Port Radium or along the uranium transportation route. We are hoping to answer some of the seventy-seven questions that were asked in the Action Plan of the Canada-Deline Uranium Table.

You are asked to complete a medical check-up at the Health Center. The check-up will be provided by a Registered Nurse and will be about one hour long. Your medical information will then be provided to the lead researcher of this study. The lead researcher will remove all personal data from the medical information.

Participating in this study will help us understand the health impacts of mining activities on Great Bear Lake. At the same time you will also learn about your personal health. Any medical follow up that is needed to maintain and improve your health will be provided to you. The medical information will also help us to plan medical follow up activities in the future.

All information will be treated as confidential, except when professional codes of ethics or the law require reporting, such as in the event of child abuse. We will use a code name instead of your name when any information is shared with others in presentations, reports or publications.

Your medical information will be stored at the Health Center with your medical file, according to Health Centre policy. A photocopy without your name attached will be stored in a locked file at the Deline Dene Band Office only during the study. The Health and Social Programs Coordinator and Research Director of the Deline Uranium Team will have access to this information until the study is complete.

You will receive a copy of the consent form. As well, you will be informed of the study results. You have the right to withdraw from the study at any time without giving a reason. As well, you have the right to refuse to answer any questions or to refuse to participate in the interview entirely. If you choose not to participate, your health care will not be affected.

## Sample Consent Form (Health Research)

<b>Part 1: Researcher Information</b>		
Project Lead	Organisation	
Contact Information		
Co-Researcher	Organisation	
Contact information		
<b>Part 2: Participant Consent</b>	Yes	No
Do you understand that you have been asked to be in a research study?		
Have you read and received a copy of the attached information sheet?		
Do you understand the benefits and risks involved in taking part in this study?		
Have you had an opportunity to ask questions and discuss the study?		
Do you understand that you are free to refuse to participate or withdraw from the study at any time? You do not have to give a reason; it will not affect your care.		
Has the issue of confidentiality been explained to you? Do you understand who will have access to your records/information?		
<b>Part 3: Signatures</b>		
<i>This study and the information sheet was explained to me by</i>		
<b>Print Name</b>	<b>Signature</b>	
<i>I agree to take part in this study and give consent to the use of a tape or transcript explained to me.</i>		
<b>Print Name</b>	<b>Signature</b>	
<i>I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate. I gave the person a copy of the information sheet and explained its content.</i>		
<b>Researcher Name (Print)</b>	<b>Signature</b>	

## **List of Terms**

Accountability

Capacity

Colonialism

Confidentiality

Consent

Discipline

Ethics

Focus group

Goal

Guidelines

Natural science

Participatory Research

Principle

Privacy

Social science

Specialist

Strategy

Values

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