"We're not going to be Guinea Pigs"; 
Community Based research in Environmental Health and Food Justice with Native American Communities

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Tsiente by St Lawrence River 
Photo by Jessica Sargent
New York State

Quebec (Districts of TsiSnaihne or “Snye” and Kanatakon or “St Regis”)

Ontario (District of Kawehnoke or “Cornwall Island”)

- New York State
- Quebec (Districts of TsiSnaihne or “Snye” and Kanatakon or “St Regis”)
- Ontario (District of Kawehnoke or “Cornwall Island”)

General Motors Foundry
(view from Gina’s front yard, Cornwall Island)
- 209 congeners
- Manufactured in mixtures – Aroclor 1248 (48% chlorine)
- Possible health effects: cancer, endocrine disruption, immune suppression, neurobehavioral abnormalities
- Bioaccumulate, biomagnify
- Animate (Chen Animacies) PCBs “migrate,” volatilize

PCBs

You probably have some too…..
ALL FISH TAKEN FROM THE ST. LAWRENCE RIVER SHOULD BE CONSIDERED CONTAMINATED.

Sturgeon Contaminated with PCBs

State Biologist Finds Poison in Two Ducks

Mohawks’ food sources threatened

Poisoned Water
Pollution Of St. Lawrence River Is Destroying Old Ways Of Life On Reservation For Mohawks

PCB level high in fish caught near St. Regis
PCBs Higher in Mohawk Breast Milk

First they polluted the rivers,
then they polluted the lakes,
and now...

PCBs Dump Poses ‘Danger to Health’

Midwife worries over high rate of abnormalities

Mohawk Life Threatened by Pollution
Katsi Cook

Woman’s Dance Project

Mother’s Milk Project

First Environment Research Project (FERP)

Iewirokas
Community Based Participatory Research (CBPR)

- SUNY Albany
- First Environment Research Project (FERP)
- Akwesasne Task Force on the Environment (ATFE)
Good Mind Research Protocol

- **Skennen** (peace) → **Kariwiio/kanikonri:io** (good word/mind) → **Kasastensera** (strength)

Peace → respect

Good mind → equity

Strength → empowerment
Potential Health Effects of Contamination:

- Diabetes
- Heart Disease
- Decreased thyroid function
- Lower testosterone
- Menarche affected
- Cognitive, memory
- Ovulation

Data collected 1985-2003 (papers published through 2012), and 2009-2013 (publications ongoing)
Health Studies

- Health study process:
  - Homes chosen random sampling
  - Series of visits by FERP employee, collect data
  - Data analyzed in Albany
  - Participants sent results letters
Methods:

- Snowball sampling
- Targeted interviews
- Visits—traded labor, met over food and coffee

- Asked about participation in health studies, changes in community food systems, threats to community health

- I interviewed 63 Akwesasronon—32 involved in studies, 6 FERP employees, 7 SUNY scientists,
Changes to Fish Consumption

- ¾ of the interviewees replied they had dramatically decreased or entirely ceased local fish consumption
  - After advisories
  - Because of changes in fish.
- Cultural obligation to keep eating fish
- Cultural impacts of ceasing fish consumption
  - Language loss
  - Loss of opportunities to connect with
Environmental Reproductive Justice

• Ensuring that a community's reproductive capabilities are not inhibited by environmental contamination

• Considering the impact of environmental contamination on the reproduction of knowledge and culturally informed tribal citizens
Indigenous Peoples of North America: Environmental Exposures and Reproductive Justice

Elizabeth Hoover, Katul Cook, Ron Plains, Kathy Sanchez, Vi Waghby, Pamela Miller, Renee Defuant, Caitlin Sidles, and David O. Carpenter

Abstract

Background: Indigenous American communities face disproportionate health burdens and environmental health risks compared with the average North American population. These health impacts are issues of both environmental and reproductive justice.

Objectives: In this commentary, we review five indigenous communities in various stages of environmental health research and discuss the intersection of environmental health and reproductive justice issues in these communities as well as the limitations of legal recourse.

Discussion: The health disparities impacting life expectancy and reproductive capabilities in indigenous communities are due to a combination of social, economic, and environmental factors. The system of federal environmental and Indian law is insufficient to protect indigenous communities from environmental contamination. Many communities are interested in developing appropriate research partnerships in order to discern the full impact of environmental contamination and prevent further damage.

Conclusions: Continued research involving collaborative partnerships among scientific researchers, community members, and health care providers is needed to determine the impacts of this contamination and to develop approaches for remediation and policy interventions.

Keywords: Alaska Natives, environmental justice, First Nations, Native Americans, reproductive justice
The diagram illustrates the Community-Based Participatory Research (CBPR) Process, which keeps research respectful, accessible, and socially relevant while also keeping research scientifically sound and academically relevant.

**Development**
- Focus of Inquiry / Problem Definition
- Study Design
- Funding
- Has Scientific Value
- Meets Funder Priorities

**Implementation**
- Recruit Participants
- Collect Data
- Analyze Data
- Ensures Safe & Scientifically Appropriate Recruitment
- Ensures Scientific Rigor

**Dissemination**
- Draw Conclusions
- Design Interventions
- Translate Findings
- Builds on Theory
- Publishes Findings
- Publicizes Findings
- Helps Community

The chart is found at: http://aaspire.org/about/cbpr.html
Reactions to Report Back

• Community members: some happy with receipt of their info, some didn’t understand what it meant (expectations of science). FERP employees found the job tricky but rewarding
• Scientists: learned a lot from having to negotiate with community, better results
• Negotiating time and ownership of data tricky
Opportunity for more personalized report back, educate whole family

Target “social body” rather than individual body

O’Neil (2004:36) “We must insist, then, that the family should be a thinking body, whose common sense should be fostered in any health community and by any practical means.”
Current health concerns: Diabetes

- ¼ of community is diabetic
- Social aspects of eating; “One dish, one spoon:
- Whole family needs to work on diet together
Centering Health Care
Oherokon: “Under the Husk”
Rites of Passage
Kanenhi:io Ionkwaienthon:Hakie
“We are Planting Good Seeds”
Political Bodies
Risk

• *Risk reduction strategies* look to risk-producers to prevent or eliminate environmental contamination in order to avoid human exposure.

• *Risk avoidance strategies* call upon the risk-bearers to alter their practices so as to avoid the harms of exposure to contamination.

• “civic dislocation” (Jasanoff 1997)
ARARS
Applicable or Relevant and Appropriate Requirements
For PCB cleanup at Akwesasne, 10x more stringent than the state and federal standards

Craig Arquette, Environmental Specialist for SRMT Envi Division
How Do PCBs Get Into the Fish I Eat?
Figure 4.2: The Grasshopper Effect

THE GRASSHOPPER EFFECT AND OUT-OF-CANADA SOURCES

Source Regions for Agricultural and Industrial Contaminants
- Agricultural
- Industrial
- Dominant Air Currents
- Atlantic Water Circulation
- River discharge

Alpha-HCH in seawater ng/litre

Concentrations of one HCH compound have been found to increase from south-to-north along a line from the Java Sea (off Indonesia and China) to the Beaufort Sea (AMAP, 1997).
remedial actions have been completed in the St. Lawrence River, Raquette River, and Turtle Cove, and, when combined with the existing fish advisories, these measures address unacceptable exposure pathways in these areas”
New Fish Advisory

Akwesasne Family Guide to Eating Locally-Caught Fish

We turn our minds to all the Fish that gave themselves to us as food and send our greetings and thanks that they continue to do so.

Saint Regis Mohawk Tribe Environment Division

Advice for the Entire Family

Eat Wisely

Best Choice for Everyone to Eat

- Brown Trout (from smaller streams)
- Brook Trout
- Yellow Perch
- Black Crappie
- Bluegill
- Brown Bullhead
- Walleye smaller than 18”
- Rock Bass
- Pumpkinseed/Sunfish

OR

Up to 8 portions a month

Up to 4 portions a month

Chinook Salmon
Coho Salmon
Rainbow Trout
Brown Trout (from St. Lawrence River)
Largemouth Bass smaller than 18”
Smallmouth Bass smaller than 18”
Walleye larger than 18”
White Sucker

OR

Up to 1 portion a month

Avoid

Muskellunge
Northern Pike
Channel Catfish
Largemouth Bass larger than 18”
Smallmouth Bass larger than 18”
Lake Sturgeon

Do Not Eat

American eel
Carp
Akwesasne Waters

LEGEND
- Fishing Access Sites
- Dams
- Marinas/Boat Launches (a fee may be charged by the marina)
- Roads

PCB Contaminated Sediment: DO NOT EAT ANY FISH from the Massena Power Canal to Raquette Point.

Rivers you CAN eat fish from: See Advice for Akwesasne Families (on back) for the wisest choices for fish type, size and portions.

1 - Long Sault Diversion Dam
2 - Massena Village Dam
3 - Massena Diversion Dam
4 - Robert H. Saunders / Robert Moses Power Dam
5 - Hogansburg Hydroelectric Dam
6 & 7 - Robert Moses State Park Boat Launches
8 - Ahnawate Marina
9 - Sit-N-Bull Campground
10 - Tacklebox Marina
11 - King's Marina
12 - Adams Marina
13 - Lewis Marine

For up-to-date information about marinas contact SRMT Economic Development at 518-358-2635 or view the Akwesasne Business Directory located at www.srmt-nsn.gov/divisions/administration/economic_development/.

Akwesasne Family Guide to Eating Locally Caught Fish, Kentenikow November 2013 is published by the Environment Division, Saint Regis Mohawk Tribe. For more information call 518-358-5907 or check online at www.srmt-nsn.org.
Ase Tsi Tewaton
Natural Resources Damages Assessment
Implications/Applications

• We need policy regulations/ direct action that will better protect the health, culture, and food sources of Indigenous communities from environmental contamination (risk reduction vs risk avoidance)

• Importance of community-based participatory research

• Important to consider settler colonial context and unique position of Tribal nations in deciding what constitutes EJ and RJ (includes ability to pass on cultural knowledge)

• Importance of highlighting survivance
the river is in us
FIGHTING TOXICS IN A MOHAWK COMMUNITY

Elizabeth Hoover
Kanenhio:io Ionkwaienthoni:Hakie
“We are Planting Good Seeds”