Citizen Science: Using Community-driven Approaches to Address Environmental Health Disparities

Community-Based Research on Sivuqaq—Protecting the Health of Future Generations

Vi Waghiyi
Environmental Health and Justice Program Director, Alaska Community Action on Toxics
vi@akaction.org

Pamela Miller
Executive Director, Alaska Community Action on Toxics
pamela@akaction.org
Our mission:
"We believe everyone has a right to clean air, clean water, and toxic-free food. Driven by a core belief in environmental justice, ACAT empowers communities to eliminate exposure to toxics through collaborative research, shared science, education, organizing, and advocacy."

Core Values:
- Community right-to-know
- Environmental justice
- Precautionary principle
- Elimination of the production and release of toxics
- Rights and sovereignty of Indigenous peoples
- Culture of caring and wellness
What do we do to achieve our mission?

- Community-based participatory research
- Respond to community calls for assistance
- Environmental health, justice, and human rights education
- Environmental health workshops
- Workshops: green cleaning, healthy homes, organic gardening
- Advocate for policy change at local, national, and international levels
Annie Alowa
we remember her knowledge and forewarning as a respected community health aide and elder

- She was a keen and trained observer about the health of her people
- She observed higher rates of cancers among the people whose families lived and worked at Northeast Cape
- She witnessed miscarriages and low birth weight babies, especially among those families closely associated with Northeast Cape
- She inspires our work everyday!
700 active and abandoned military sites in Alaska—Many co-located with Alaska Native villages

Summary of Toxic Waste Sites in Alaska

- All ADEC contaminated sites
- Military, FAA, USCG, & Commerce
- Superfund sites
- Radioactive waste sites
- Chemical weapons dumps

EPA Sites
- NPDES (116 sites)
- CERCLA (229 sites)
- RCRA (19 sites)
- TRI (25 reported sites)

Towns
Trans-Alaska Pipeline

Norton Sound

ACAT
GIS Mapping
Alaskans and other northern peoples are especially affected:

- The north has become a hemispheric sink for industrial chemicals
- Northern/Arctic food webs favor the deposition and retention of persistent, bioaccumulative toxics
- Contaminants in the north threaten the health of people who rely on traditional diets of fish and marine mammals.
- Global warming is exacerbating the transport and mobilization of contaminants into and within the Arctic.
ENVIRONMENTAL EXPOSURES IN THE NORTH

• Persistent organic pollutants (POPs) migrate from lower latitudes and settle in the northern latitudes and Arctic

• People in the Circumpolar North face disproportionate exposures to toxic chemicals, and children are at highest risk

• Arctic Indigenous Peoples who rely on a traditional diet are particularly vulnerable to exposure

• Arctic Indigenous Peoples have been found to have levels of POPs concentrations in blood and breast milk that are among the highest of any population on Earth
Where is Sivuqaq (St. Lawrence Island)?

Located in the Northern Bering Sea
Voices of Our Ancestors
Traditional ecological knowledge is the foundation of our community-based research

"We have always been a vigilant people. Our community-based research enables us to be vigilant at the molecular level."

Merle Apassingok, Native Village of Gambell, member St. Lawrence Island Working Group
White Alice Communication Site, operational 1957-1972
Above ground structures & debris removed in 2003
$123 million spent on site remediation
Community-based Research on Sivuqaq, Alaska

- Elder interviews
- Bird eggs (murres)
- Human blood serum (PCBs, PBDEs, pesticides, PFCs)
- Air (PCBs, pesticides)
- Groundwater (VOCs)
- Surface water (PCBs, PAHs, pesticides)
- Edible plants (PCBs, pesticides)
- Sediment cores (PCBs, pesticides, trace metals)
- Traditional foods (PCBs, pesticides, metals)
- Stickleback as sentinel species
- Community health surveys
- Community Cancer Registry
- Household dust (PBDEs and PFCs)
PCBs in Blood Serum of St. Lawrence Island People

- Levels of PCBs in the blood of St. Lawrence Island Yupik people **4.5-9 times higher** than average in lower-48 populations
- Evidence of PCBs accumulating in the Arctic via global transport
- Military contamination also a significant source
- Published in the *International Journal of Circumpolar Health* (Carpenter et al., 2005)

![Graph showing PCB concentrations in different locations](image)

**Average for populations in the Lower 48**
Meats – ND (Walrus) - 102.83 ppb (Bowhead)
Fat/Blubber – 0.22 (Reindeer) ppb – 582.68 ppb (Polar Bear)
Organs - ND (Reindeer liver, kidney) – 161.02 ppb (Bearded Seal Skin)
Plants — 0.01 ppb (Greens) - 3.65 ppb (Salmon Berries)
Marine Invertebrates — 0.18 ppb (Crab Meat) – 4.74 ppb (Sea Peaches/Upa)
Health Patterns of Concern

- Cancers
- Thyroid disease
- Diabetes
- Heart disease
- Birth defects, low birthweight babies, premature births, stillbirths, miscarriages
- Other reproductive health problems
Multi-generational effects

- Military displaced the Native Village of Northeast Cape
- 130 people lived in community
- Diseases more prevalent among these families today
Community-based Research Institute
Tribal Community Forums and Indigenous Women’s Gathering
Organizing with Youth, Women, and Elders to Achieve Health, Human Rights, Environmental and Reproductive Justice

Human rights training for youth

ACAT staff and board with U.N. Rapporteur on the Rights of Indigenous Peoples

Indigenous Women’s Gathering
Some key findings concerning sentinel fish species

- Despite extensive site remediation of the former military site at NE Cape, stickleback and blackfish remain heavily contaminated with PCBs.
- PCBs disrupting endocrine function of fish (thyroid, reproductive) and decreasing expression of genes important in repairing gene mutations.
- Vitellogenin concentrations in male stickleback indicate exposure to estrogenic contaminants (certain PCB congeners).
- Widespread health disruption in the fish is consistent with health problems of people on the island. Stickleback are an important sentinel species.
- This study demonstrates that, even after site remediation, contaminants from Cold War FUD sites in remote regions of the Arctic remain a potential health threat to local residents; in this case, Yupik people who had no influence over site selection and use by the United States military.
- Exceptionally high levels of PBDEs (especially BDE-47) and PFAS (especially PFOS and PFNA) in stickleback of Troutman Lake indicate local source, such as landfills.
Research in Arctic environments and people demonstrates:

- Higher PBDEs concentrations found in Inuit children than adults, and higher PBDE levels than those reported for many children around the world (O’Brien et al., 2012)

- Levels of PBDEs found in the blood of Yupik people of the Yukon-Kuskokwim Delta region of Alaska are the highest known human PBDE concentrations in the Circumpolar North (AMAP, 2014)

- ACAT research found PBDEs are ubiquitous in dust collected from SLI households, with concentrations of several PBDEs in dust associated with serum concentrations (Byrne et al., 2017)

- ACAT also found associations between PBDEs in serum and thyroid hormone levels in SLI communities (Byrne et al., 2017)
Key findings concerning human exposures

- All sampled homes had detectable concentrations of PBDEs in the dust. Twenty-one individual congeners were present in 100% of the dust samples.
- Six PBDEs were detected in 100% of the serum samples and another ten were present in 95% of the serum samples. The levels are within the range reported in the U.S. lower-48. Serum PBDEs are higher than those of Canadian Inuit.
- PFOS and PFNA were detected in more than 98% of the serum samples and PFOA was detected in 92% of the samples.
- Serum PFAS also comparable to levels in the U.S. general population, however PFNA and PFUnDa elevated.
- We demonstrated that certain PBDE congeners and PFAS disrupt thyroid homeostasis.
Community-Based Participatory Research and Policy Engagement

- Foundation of elder knowledge and community leadership
- Fostering collaborations with academic researchers
- Training of community health researchers
- Emphasis on community-right-to-know, capacity building, and empowerment
- Community-based Research Institute
- Training for health care providers
- Hold the military accountable for responsible clean up
- Work on policy change at state, national, international levels
Implications for Public Health and Policy

Community-based participatory research:

- Informs remediation decisions
- Ensures effective regulatory oversight and accountability
- Promotes environmental health through better diagnoses and treatment
- Influences public health policy to prevent exposures from formerly used defense sites and long-range transport
Policy achievements—local, state, national, international

- Holding military accountable--$123 M in cleanup for NE Cape
- Passage of the “Protecting the Health of Children and Firefighters” Ordinance—2019
- Introduction of Toxic-Free Children’s Act—2019
- Protection of vulnerable populations in Lautenberg Act (TSCA reform)—2016
- Negotiation of the Stockholm Convention and global bans on pesticides and industrial chemicals that harm Arctic communities—2009-2019
Challenges in oversight and regulation

- Lack of regulatory oversight
- Burden of proof on communities
- Cleanup standards insufficient to protect health
- Tribes not included in Records of Decision
- ATSDR Health Consultation ignored community knowledge of health and disease patterns
- State cancer registry data do not account for numbers and types of cancers observed by people of Sivuqaq
- Chemicals policies at all levels are not protective of health
The Language of the Stockholm Convention

- “Aware of the health concerns…in particular impacts upon women and children and, through them, upon future generations.”
- “Conscious of the need for global action…”
- “Acknowledging that precaution underlies the concerns of all the Parties and is embedded within this Convention…”
- “Determined to protect human health and the environment…”
- “Acknowledging that the Arctic ecosystems and Indigenous communities are particularly at risk…”
“The chemicals present in our bodies are passed onto our Indigenous children and harm their ability to learn our languages, songs, stories, and knowledge.”
Role of Science in Community-Based Research

- Respond to requests for technical assistance
- Answer questions of concern to community with tools such as air/water/soil sampling, analysis of traditional foods, contaminant levels in people, research on endocrine disruption,
- Document harm to health and environment
- Collaborate, corroborate, compliment traditional knowledge
- Challenge assumptions made in simplistic, pseudoscientific risk assessment models used by regulatory agencies and polluters
- Hold polluters accountable
- Science to action—inform health interventions and change policy and regulations in order to protect health
Recommendations

▪ Community drives the research from inception, including development of research questions, design of research, training, sampling, data interpretation, research translation, reporting back, ownership of data
▪ Ensure equity of community and academic research partners
▪ Academic and community partners work together as allies to address health disparities
▪ Science to action—informs systemic change needed to protect health of vulnerable populations; based on the precautionary principle
▪ Enact comprehensive chemicals policy reform at state, national and international levels necessary to protect vulnerable populations and prevent disease. Hold polluters accountable.
▪ Public health and regulatory agency officials must recognize that traditional knowledge is critical when assessing the health of tribal communities.
▪ Science and public health communities work with community partners to create a responsive, integrative, and inclusive health care system that incorporates traditional healing, primary prevention, diagnosis, and treatment to protect the health and well-being of present and future generations.
Working for the Protection of Present and Future Generations
Publications


- Byrne, s et al. 2018 Exposure to perfluoroalkyl substances and associations with serum thyroid hormones in a remote population of Alaska natives. *Environmental Research*. In process
Thank you. Igamsiqayugviikamsi

- NIEHS R01ES019620
  Protecting Future Generations

- Native Villages of Savoonga and Gambell
- University at Albany
- Northern Arizona University
- University of Alaska
- Indiana University
- University of Oregon
- Wadsworth Lab