Welcome to the CLU-IN Internet Seminar

Community Engagement Activities in Native American Communities

Sponsored by: National Institute of Environmental Health Sciences, Superfund Research Program

Delivered: May 23, 2011, 1:00 PM - 3:00 PM, EDT (17:00-19:00 GMT)

Instructors:

Anna K. Harding, Department of Public Health, Oregon State University, (Anna.Harding@oregonstate.edu)

Barbara Harper, Department of Science and Engineering, Confederated Tribes of the Umatilla Indian Reservation, (bharper@amerion.com)

Laurel Schaider, Department of Environmental Health, Harvard School of Public Health (lschaide@hsph.harvard.edu)

Jim Shine, Department of Environmental Health, Harvard School of Public Health (jshine@hsph.harvard.edu)

Moderator:

Charles Maurice, U.S. EPA, Region 5 (maurice.charles@epa.gov)

Visit the Clean Up Information Network online at www.cluin.org

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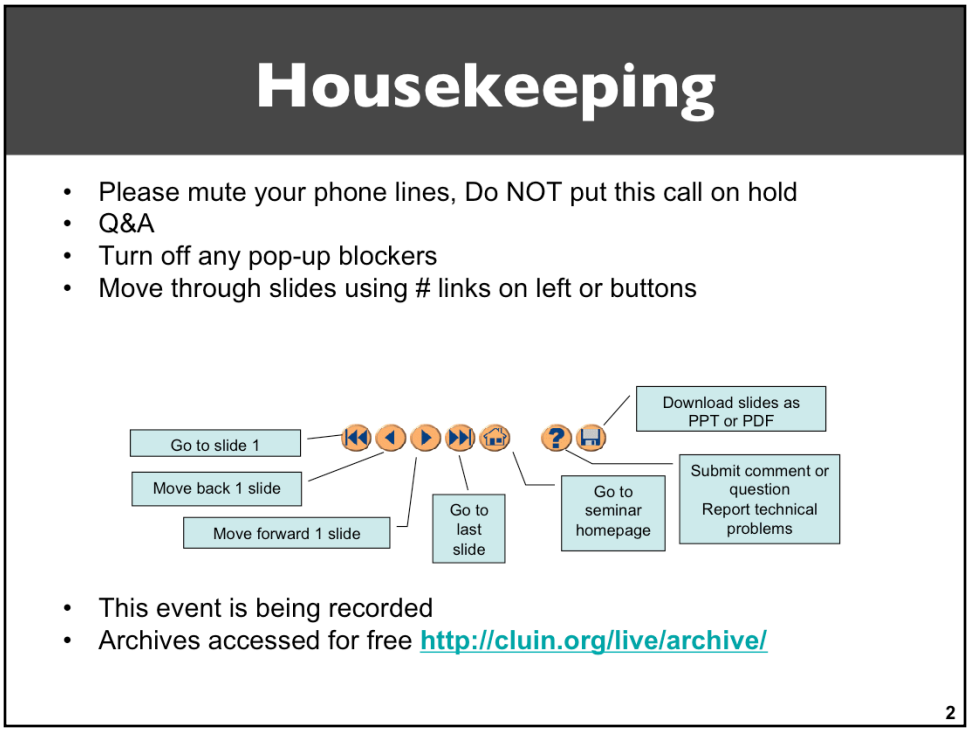

Although I'm sure that some of you have these rules memorized from previous CLU-IN events, let's run through them quickly for our new participants.

Please mute your phone lines during the seminar to minimize disruption and background noise. If you do not have a mute button, press *6 to mute #6 to unmute your lines at anytime. Also, please do NOT put this call on hold as this may bring delightful, but unwanted background music over the lines and interupt the seminar.

You should note that throughout the seminar, we will ask for your feedback. You do not need to wait for Q&A breaks to ask questions or provide comments. To submit comments/questions and report technical problems, please use the ? Icon at the top of your screen. You can move forward/backward in the slides by using the single arrow buttons (left moves back 1 slide, right moves advances 1 slide). The double arrowed buttons will take you to 1st and last slides respectively. You may also advance to any slide using the numbered links that appear on the left side of your screen. The button with a house icon will take you back to main seminar page which displays our agenda, speaker information, links to the slides and additional resources. Lastly, the button with a computer disc can be used to download and save today's presentation materials.

With that, please move to slide 3.

Addressing Tribal Exposures to Polycyclic Aromatic Hydrocarbons (PAHs) and Building Tribal Capacity though a Tribal-University Partnership

Superfund Research Program Risk e-Learning Webinar
May 23, 2011

Anna K. Harding[1], PhD and Barbara L. Harper,[1,2] PhD

[1]Oregon State University
[2]Confederated Tribes of the Umatilla Indian Reservation

Confederated Tribes of the Umatilla Indian Reservation

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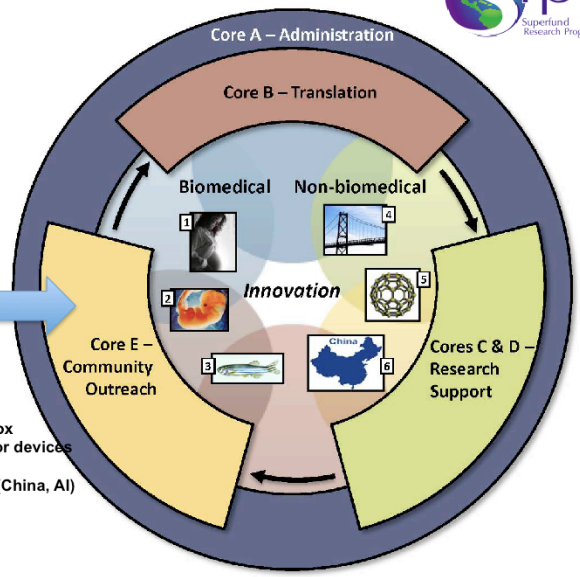
Oregon State University awarded SRP in 2009 focused on PAHs: "New Technologies and Emerging Health Risks"



Research Projects:
1. PAH mixtures as transplacental & dermal carcinogens
2. Transplacental Dosimetry of PAHs
3. Mechanisms of PAH-induced dev tox
4. Dev of biological response indicator devices
5. Nanomaterial PAH--discontinued
6. PAHs highly exposed populations (China, AI)

Core A - Administration
Core B - ResearchTranslation
Core C - Analytical Chemistry
Core D - Biostatistics & Bioinformatics
Core E – Community Engagement

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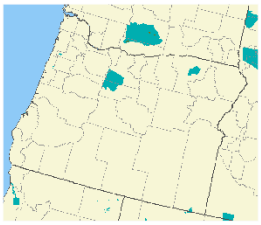
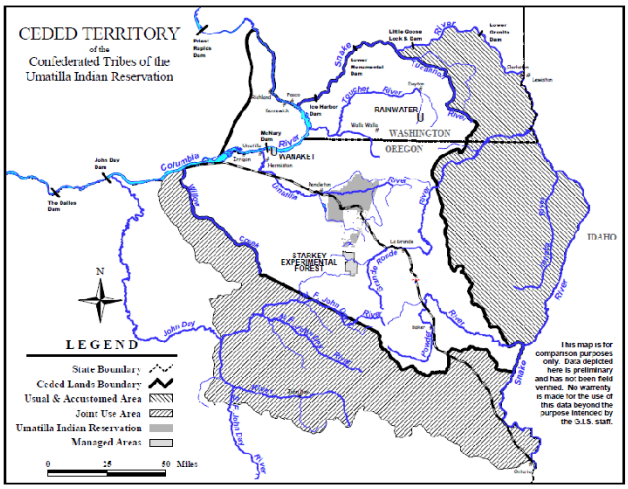
Location of the Confederated Tribes of the Umatilla Indian Reservation (CTUIR)





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History of Collaboration between OSU and CTUIR

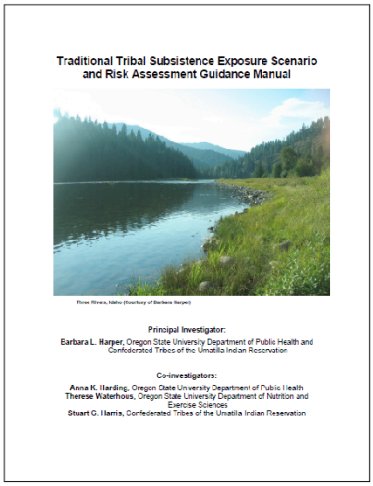
• EPA-STAR-J1-R831046 (2003-2006) "Estimating Environmental Exposures for Tribes Practicing Traditional Subsistence Lifestyles"

1) Cross-cultural methods
2) Research results for specific exposure pathway parameters

http://www.hhs.oregonstate.edu/ph/sites/default/files/xposure_Scenario_and_Risk_Guidance_Manual_v2.pdf

• OSU and CTUIR (Department of Science and Engineering--DOSE) have a signed MOU in place

•DOSE and OSU-Public Health have worked on several other pilot projects together


Traditional Tribal Subsistence Exposure Scenario and Risk Assessment Guidance Manual

Three Rivers, Idaho (Courtesy of Barbara Harper)

Principal Investigator:
Barbara L. Harper, Oregon State University Department of Public Health and Confederated Tribes of the Umatilla Indian Reservation

Co-investigators:
Anna K. Harding, Oregon State University Department of Public Health
Therese Waterhous, Oregon State University Department of Nutrition and Exercise Sciences
Stuart G. Harris, Confederated Tribes of the Umatilla Indian Reservation

Governance - Securing the Homeland

Governance for the people, by the people:

- Support the infrastructure for commerce
  - Provide services for the population
- Provide for the well-being of the people
- Set bounds, protect rights and resources

Utilities
Clothing
Language
Shelter
Workforce
Land Base
Domestic violence
Offices
Religion
Justice
Roads
Food
Friends
Clinic
Safety
Investments
Social Services
Cultural Resources
Education
Potholes and stop signs
Emergency Preparedness
Clean Water
Energy
Insurance
Fairness
Truancy
Voting
Connectivity, Communications
Water & sewer

Securing the Future

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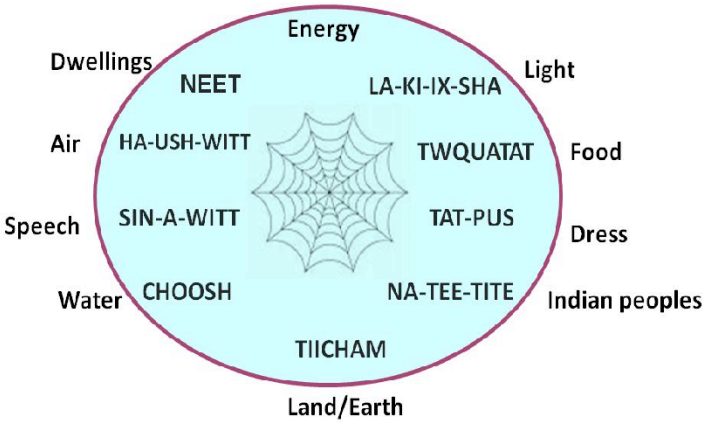
CTUIR 2010

Governmental Context

- Not just a “tribal community” but also a sovereign government with laws, Treaty, inter-governmental relations. CBPR/GovBPR.
- Tribes are the only ones with authority to “speak for” the tribe as an entity.
- There may be Tribal policies and plans already in motion. The Tribe may not be ready for a particular project.
- The Tribe may have higher priorities for their limited staff.
- The Tribe may simply choose a different path.
- There may be government-to-government regulatory negotiations underway (at contaminated sites).

Tamánwit (natural law - CTUIR)

World View – TEK – Ways of knowing and relating,



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Health means healthy people in a healthy environment participating with the community in an eco-cultural system following natural laws in seamless cycles.

Educating OSU Community about Tribal Research Issues

Tribal Research Symposium April 2010

- Engagement Core (with help from NIEHS-funded Environmental Health Sciences Center sponsored symposium at OSU on issues/perspectives related to research in Tribal communities
- Included Tribal legal issues, research ethics, concepts in indigenous and western science, integration of socio-cultural health indicators into Tribal risk research.
- Featured speakers from CTUIR and Swinomish Tribal Community and tribal legal scholar
- Presentation and speaker details: http://oregonstate.edu/superfund/outreachevents

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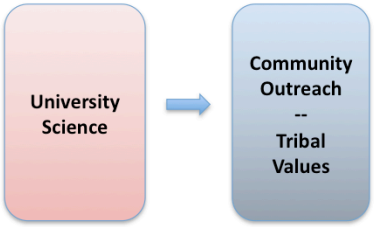
Matching Tribal Goals with SRP Project Goals

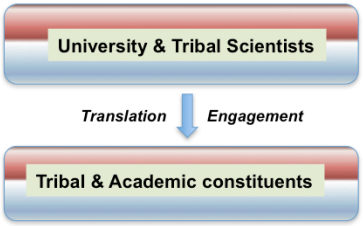
• Challenge was to match up needs and goals of CTUIR with that of other projects in SRP and dealing with reviewer expectations about role of community-based research in Engagement Core.
• CTUIR has research and data needs of its own and capacity of its own; were not at all interested in educational materials or health advice, for example, that might have been prepared by the Research Translation Core and implemented by the Engagement Core.

Community Engagement Models

Information Transmission Model



Dual-Capacity Model



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CTUIR Needs for the Collaborative Project

- PAH exposures related to ambient air (field burning, wood burning fireplaces, diesel truck stop, downwind from coal burning power plant)
- Analysis of PAHs from the traditional smoking practices of fish and game to better understand personal exposures during these activities
- Concentration of PAHs in smoked fish
- Archival review at Tamástklict Cultural Institute to determine other food preservation/preparation methods for future studies

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Capacity Building

- Getting information the community/nation needs and solutions that fit the cultural and governance situation
- Getting numerical data
- Acquiring analytical and research skills by a department, not just a single individual.
- Getting equipment to use in-house (labs at tribes)
- Getting training and student opportunities, STEM programs
- Continuity of projects, staff, and knowledge
- Funding for projects, set-asides for tribes
- Quality staff willing to accept relatively low salaries
- Experience with federal negotiating (fair treatment, meaningful involvement).
- Building cultural competence in universities and agencies

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Engagement Core Project Goals

Establish a collaborative project that includes the Confederated Tribes of the Umatilla Indian Reservation (CTUIR) tribal agencies, tribal and university investigators, and tribal community members to <u>better understand health risks associated with PAH exposure on the Reservation and to assist in human capacity building with tribal partners.</u>

Project aims/activities in a nutshell:

- Meet on annual basis with interdisciplinary advisory group that will provide overall guidance to project
- Assess PAH exposures of concern to the Tribes related to ambient air and traditional and cultural practices
- Measure PAH concentrations in foods prepared using indigenous smoking preservation methods
- Develop culturally appropriate risk reduction approaches and outreach strategies that engage the community and offer the best opportunity for improved health

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Aim 1: Tribal Advisory Committee

Establish and convene an interdisciplinary advisory group representing tribal and government agencies, and other members who will add additional expertise in tribal cultural lifestyles and culturally-appropriate risk reduction measures.

- Membership includes representatives from Yellowhawk Tribal Health Clinic, CTUIR community, OSU, OHSU, Swinomish Tribe
- 2nd annual meeting in October 2010 at OSU—SRP lab tours
- Meeting minutes posted:

http://ehsc.science.oregonstate.edu/files/ehsc/AgendaOct52010_final.pdf

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Aim 2: Capacity Building and PAH Exposure Assessment

Engage in human capacity building with the CTUIR tribal partners and assess PAH exposure pathways specific and relevant to their traditional and cultural practices.

Three tasks:

- Ambient air monitoring on the Reservation
- Personal air sampling during smoking of fish
- Measurement of PAHs in smoked fish

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Aim 2: Ambient Air Monitoring on the Reservation

OSU researchers helped set up a regional ambient air monitoring station on Umatilla Indian Reservation

OSU installed Hi-Vol air samplers to monitor for daily 24-hr PM size segregated samples during multiple seasons. CTUIR downloads data; sends filters to OSU for chemical analysis.

Adds capacity to existing AQ monitoring:

- Examine differential PAH profiles to determine combustion source (diesel, coal, biomass, etc.)
- Complement current Tribal monitoring and implementation of Federal Air Rules for Reservations (CTUIR has received TAS and partial delegation)
- CTUIR keeps the equipment.

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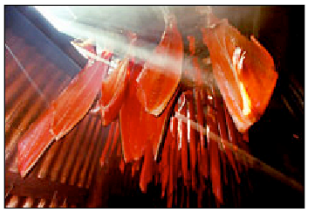
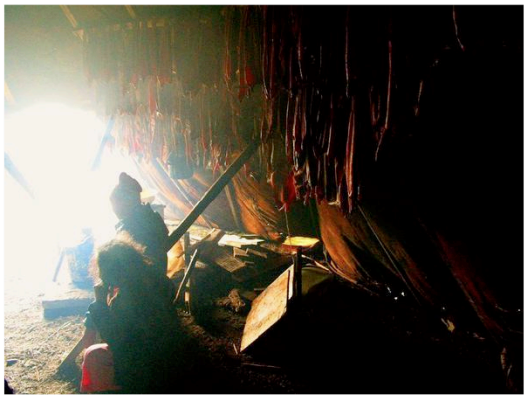
Smoking Salmon

- Exposure of the smokers
- PAHs in foods





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Aim 2: Collection and Analysis of Personal Air Samples from Tribal members smoking food

- OSU and CTUIR conducting personal air sampling during food smoking activities in traditional Tribal smokehouses.
- Personal air sampling equipment will be owned by the CTUIR and used by Tribal members to measure exposure during food smoking
- Additional activity: Collection of air samples from smoke structure using Passive Sampling Device (PSD) (Project 4). PSDs have been set up to get background data before the smoking begins
- Food smoking will be conducted in two structures (wood smoke shed and teepee) and using three different woods typically used by the Tribes (alder, ash, apple)

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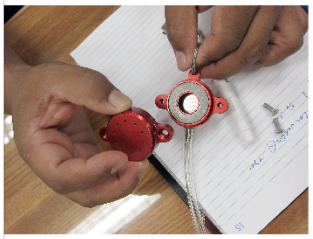
Aim 2: Personal Exposure Monitoring

CTUIR and OSU will collect air samples during smoking of fish using a small Leland personal monitoring system.

Tribal members trained in proper methods of personal air sampling.

Personal air training video:
http://oregonstate.edu/superfund/training-using-personal-air-sampling-devices

Example of CTUIR capacity building



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Aim 2: Collection & Analysis Urine Samples

- Collection and analysis of urine samples from non-cigarette smoking Tribal members smoking food (before-after activity) using an isotope-dilution GC/HRMS method (Core D conducts analysis)
- Survey with participants who are smoking foods who submit urine samples to determine job position, verify non-smoking status, gender, other possible exposures to tobacco smoke (e.g., secondhand smoke)
- Received IRB approvals from OSU, Portland Indian Health Board, and approval from the CTUIR Health Commissions—at least 6 months to complete these approvals
- Food smoking activities to start spring 2011, with spring run of Chinook salmon (mid-May)

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Aim 2: Measure PAHs in Smoked Fish

Measure PAH concentrations in foods (fish, game) from indigenous smoking preservation methods.

Collection of Food Samples

- Measure PAHs in salmon after they have been preserved using indigenous smoking methods.
- Acquire samples in spring 2011 and fall 2011 salmon runs—will purchase from Tribal commercial fisherman
- Cores B, C, and D developed sampling matrix for smoked fish samples

PAH Analysis of Food

- To be conducted in Core D Laboratory – Core D has developed methods for testing fresh and smoked salmon
- Expect to test up to 90 food samples for 9 parent PAH compounds found in CDC Human Exposure Study

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Aim 3: Risk Reduction Approaches and Outreach Strategies

Develop culturally appropriate risk reduction approaches and outreach strategies that offer the best opportunity for improved health.

Develop community definition of health and well-being (eco-cultural well-being)

– Focus group survey developed to define individual and community physical, social, cultural, ecological well-being, access to cultural & natural resources.

– Working on best way to recruit participants

Select appropriate public and medical health metrics related to overall cultural and community well-being

- Examine clinic data for suitability of health statistics to develop overall picture of general health conditions for the Tribes-- feasibility of this still being discussed with new leadership at Yellowhawk Tribal Health Clinic

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Aim 3: Risk Reduction Approaches and Outreach Strategies

Engage community in designing risk reduction and health promotion strategies that gained from prior tasks and from Center's findings —Year 4

Disseminate Culturally appropriate risk reduction information both locally and more broadly to regional and national Tribal communities—Years 3-4

Examples:

Meet regularly with members of Tribal Health Commission,Yellowhawk Clinic medical staff, and Tribal Board of Trustees throughout project

Develop public service announcements; write articles for confederated Umatilla Journal

Regional and national forums through which information generated from the Engagement Core will be disseminated to other Tribes

Publications and presentations

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Integration with Other SRP Collaborators

- Core B (RTC)—participation in Core meetings, advisory meetings, facilitate technology transfer of air monitoring methods to Tribal partners; interpret data, assessment of exposure and risk, dissemination of information; purchase of personal air monitors
- Project 6--setting up ambient stations, purchasing ambient monitoring equipment, collection of air and urine samples, training tribal air staff
- Core D—processing of air, food, and urine samples
- Will use toxicity findings gained from projects applicable to human health– Projects 1, 2, 3
- Core C for computational support, data storage, and consultative data analysis, statistics
- Project 4 (PSDs) being set up in smokehouse structures
- Co-authorship of publications—Members of CEC, RTC, CTUIR, Projects 4 & 6

Material and Data Sharing Agreement

"No, it's MY data!"

Material and Data Sharing Agreement

Core developed unique agreement signed by all three parties—CTUIR, OSU, PNNL and is used by all in SRP who are working with CTUIR data. Also been adapted for other Tribal projects

Material and Data supplied by CTUIR to OSU or to PNNL, or collected by OSU on behalf of CTUIR, is and remains the property of CTUIR and shall not be shared with third parties without the written permission of CTUIR. Participant data shall not be sold or used, internally or externally, for any purpose not directly related to the scope of work defined in this agreement without the written permission of CTUIR.

All publications and presentations developed using materials or data collected under this Agreement must be presented to Director of the Department of Science and Engineering, CTUIR for review and approval prior to dissemination.

Material and Data Sharing Agreement

Material and Data Sharing Agreement have the following components:

- General project scope and collaborator.
- Types of material and data collected: States the types of material and data to be collected and the general collection method.
- Constraints on material and data use: Materials and data supplied by the tribe to researchers, or collected by researchers on behalf of the tribe, are and remain tribal property and are not to be shared with third parties without the written permission of tribal authorities. Includes procedures for publication and post-completion return of all materials and data.
- Data access and security: Details the procedures for maintaining the physical security of the data. Restricts data access to approved project researchers who require it for a specific task.
- Risks and benefits of research to the tribal community: Summarizes the risks and benefits to be expected from participation in the research project, for both the individual and the tribal community.
- Agreed-on mutual review processes: As a two-way document, the CTUIR agreed that it has equal responsibility for timely completion of research tasks and reports.

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Ethics and Informed Consent

IRB rules arose from abuses and bad outcomes. These are well known. IRB rules for extra effort at informed consent are not quite as clear.

IPR rules from anthropology and indigenous medicinal knowledge of plants are more recent. *Example:*

- Stories and songs may be 'owned' by individuals, yet professors of anthropology make careers of recording and publishing them. Or digging up tribal ancestors. Or 'discovering' tribal ideas/methods/data and publishing them.

Ethics and Informed Consent

IRB

Extra effort at informed consent and identifying potential risks

IPR

Data ownership;

Publication rules

Sovereignty

Governmental & regulatory context; Cross-cultural history, psychology, world view

Free prior informed consent

Bio-piracy

Conclusions—Key Points

- Research in tribal communities may need tribal government approval, unlike other American communities.
- Establishment of a trusting relationship between university and tribal researchers is necessary for collaborative research to succeed.
- Tribal staff and schedules and research needs may not match grant goals or funding agency schedules—adjustments may be required.
- University researchers engaged in tribal projects should become familiar with sovereignty, ethics and informed consent, and intellectual property rights.
- Some tribes already have capacity as co-investigators, and do not wish to be just recipients of information from an outreach task.
- NIEHS should consider the broad definition of "community engagement" to allow tribes or communities to do their own research. This may not be glamorous or cutting edge research, but may be an urgent data gap from a tribal perspective.

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Acknowledgements

Other Engagement Core key personnel
Stuart Harris, CTUIR
Dave Stone, OSU RTC
Sandra Uesugi, OSU
Jack Butler, CTUIR

Other OSU SRP investigators, especially:
Staci Simonich, Yuling Jia, Kim Anderson, Dan Sudakin, Katrina Waters, Andres Cardenas (MPH student)

Tribal Advisory Committee members, especially Michelle Burke, CTUIR

NIEHS funding—Award No. P42ES016465

Justin and Risk e Learning Webinar series

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Fate and Exposure Studies of Metals in Rural Oklahoma: Engaging Communities

Jim Shine and Laurel Schaider

Harvard School of Public Health, Boston, MA

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Overview

I. Study area
II. Tar Creek Superfund Site
III. Grand Lake Watershed Mercury Study
IV. General conclusions

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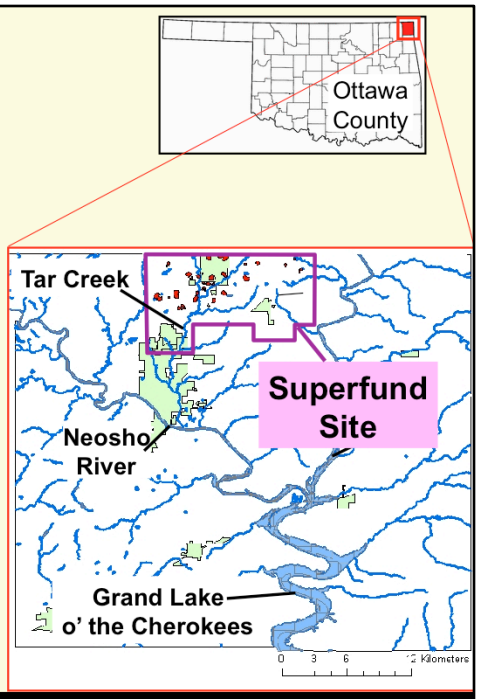
Study area

Tar Creek Superfund Site

- Tri-State Mining District
- Abandoned in 1970s
- Added to NPL in 1983



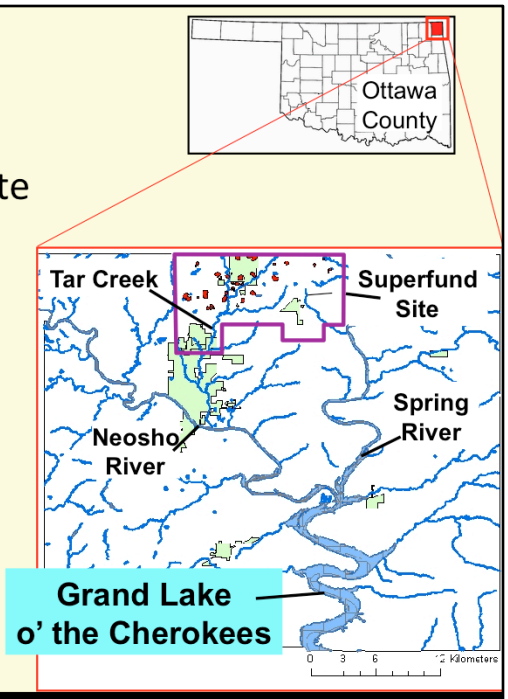
Study area

Tar Creek Superfund Site

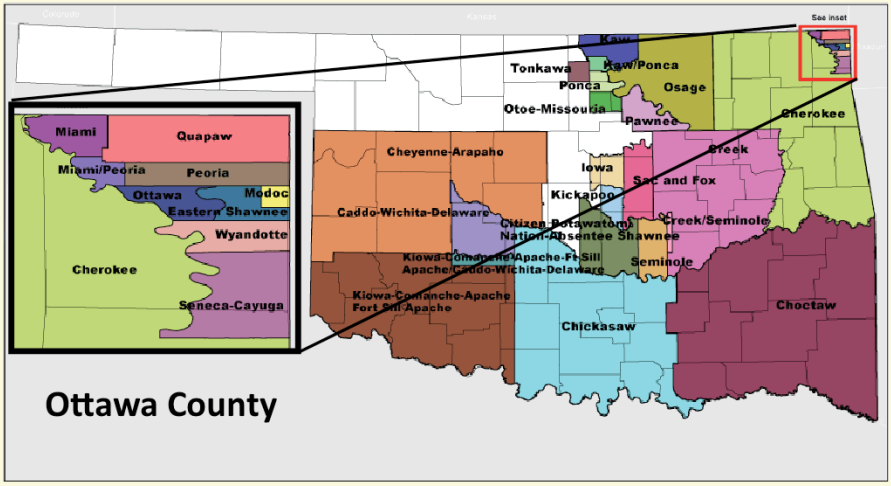
- Tri-State Mining District
- Abandoned in 1970s
- Added to NPL in 1983

Grand Lake watershed

- Reservoir on Grand River
- Popular for fishing
- Nearby power plants



Tribal lands in NE Oklahoma



Source: http://www.fema.gov/hazard/portal/oklahoma/tribal_areas.shtm

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Part I. Study area

American Indians in Ottawa County

- 17% of population in Ottawa Co. (8% statewide)
- 9 tribes
  - Cherokee
  - Eastern Shawnee
  - Miami
  - Modoc
  - Ottawa
  - Peoria
  - Quapaw
  - Seneca-Cayuga
  - Wyandotte
- Bureau of Indian Affairs and history of mining

Source: http://tarcreekfilm.com/photos/

Metal fate and transport, Tar Creek Superfund Site

- 33 major mine waste ("chat") piles
- Ongoing metal contamination
  - Lead, zinc and cadmium
  - Dust and runoff from chat piles
  - Mine drainage
- Human health concerns
  - Elevated childhood blood lead
  - Potential effects of heavy metals

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Research objectives

- Conduct fate and transport studies
  - In-stream metal transport
  - Metal speciation in mine waste
  - Metal transport to floodplain
  - Accumulation by plants
- Develop interdisciplinary research projects as part of EPA- and NIEHS-funded Children's Center
- Address community concerns regarding metal exposure

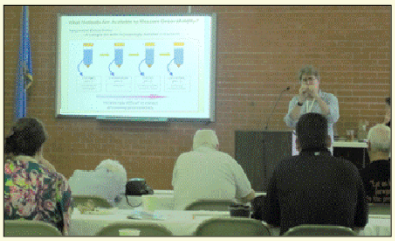
Community's perspective

- Slow progress in site remediation
- Distrust of regional EPA and state agencies
- Distrust of outside academic researchers

- Community's initial expectations from us
  - We would fix the problem
  - We would be an ally against government agencies

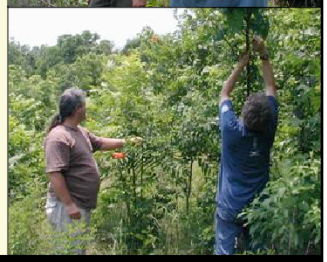
Developing partnerships

- Building understanding takes time and being present
- Local partner organization – LEAD Agency
  - Input on study design and selecting sampling sites
  - Assisted with access to some sites
- Presented research findings
  - Community advisory board
  - Tribal advisory council
  - Local community conference
  - Town officials



Interactions with tribes

- Tribal advisory council
- Some tribes welcomed our involvement
  - Measuring heavy metals in culturally-relevant plants
- Community partners made posters with results for asparagus



Constraints to Interactions:

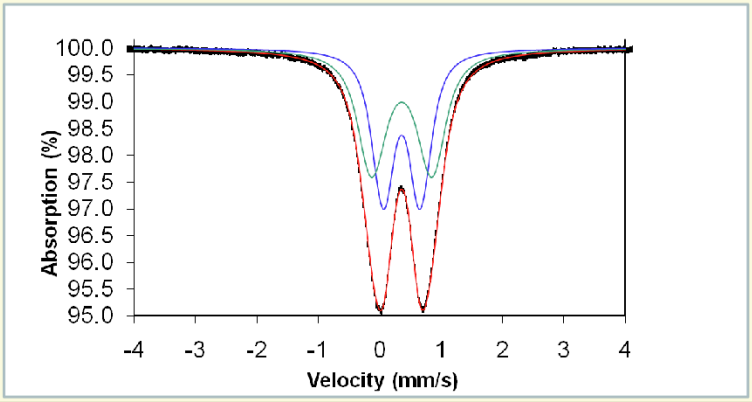
An Environmental Scientist is not an Environmentalist.

More Constraints

Scientists are often more interested in questions than answers.

Even More Constraints

The academic reward structure is not conducive to interdisciplinary problem solving.



Overcoming Constraints: The Way Forward

Be present. Pollution is not an abstract concept.

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Part II. Tar Creek Superfund Site

Overcoming Constraints: Making It Work

Quid pro quo. Understand each other's needs.

Overcoming Constraints: Making It Work

Plants
The Flood
Tree Cutting/Burning
Figuring Out the Right Questions



Grand Lake Watershed Mercury Study

- Community concerns about mercury exposure
  - Subsistence (including Indians, Micronesians and Hispanics) and recreational fishing
  - 6 coal-fired power plants in 60-mile radius
- Funded by NIEHS Partnerships for Environmental Public Health program

Source: www.industcards.com/st-coal-usa-ne-ok.htm

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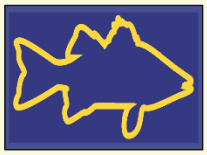
3 components of study

1. Community

   Involve community members in all aspects of study design and implementation

2. Participants

   Measure mercury exposure in people who eat fish from the watershed



3. Fish

   Measure mercury accumulation in fish throughout the watershed

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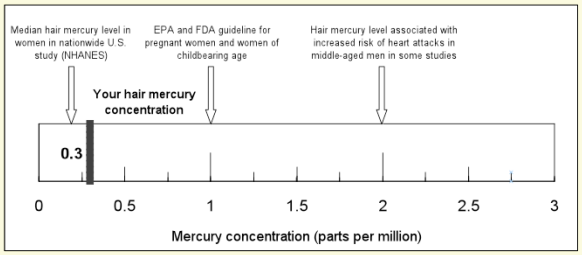
1. Community involvement

- Approaches for getting input
  - Community advisory board
  - Fishing advisory council
  - Focus groups

- Study design and implementation
  - Designing food frequency questionnaires
  - Recruiting participants
  - Collecting fish samples
  - Outreach and education

2. Assessing mercury exposure

- Target: 150 participants
- Seasonal assessments of exposure (5 times)
  - Food frequency questionnaires
  - Hair samples as biomarkers of mercury exposure
- Participants receive results of mercury hair tests



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Part III. Grand Lake Watershed Mercury Study

Recruitment strategies

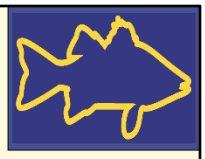
- Personal networks
- Press events for local media
- Fishing-related events and venues
- Local fishing and environmental organizations
- Powwows, churches
- Schools
- Website

Source: http://drippingspringsresort.com/?page_id=64

Challenges with recruitment

- People aren't used to participating
- Identifying high-end fish consumers
- Building connections with Micronesians
  - Language and cultural barriers
  - Engaging Micronesian high school students has helped build bridge into community

3. Fish study



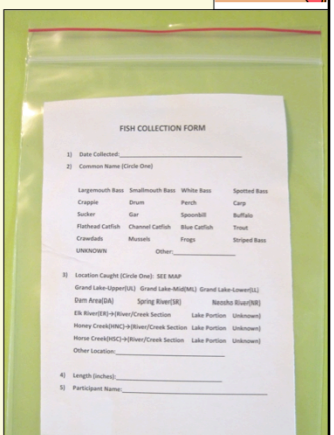
- Measure mercury levels in commonly-consumed types of fish
- Compare mercury levels in different locations
- Incorporate information about ecology and food webs to help interpret results
- Test for elevated levels of metals associated with the mining sites

Why involve community in fish collection?

- Reduce sampling requirements
- Greater buy-in from community
- Opportunity for report-back
- Increased awareness about our study and fish consumption advisories
- Builds trust with potential participants

How to involve community?

- Current and potential participants
- Fishing tournaments and boating docks
- Personal connections



Fish collection bag with form

Local government agencies

- Oklahoma Department of Wildlife Conservation
  - Paddlefish processing station
  - Analyze by-catch from population surveys
  - Our results complement theirs and enhance their mission
- Grand River Dam Authority
  - Access to their lab, boat facilities, staff time
  - We offered to share our results
- Oklahoma Air Quality Advisory Council
  - Authority to regulate mercury in the state
  - Study team member is council member

General conclusions

- Developing community partnerships requires:
  - Time
  - Patience
  - Presence
  - Openness
- Benefits
  - Better study design
  - Access to some sites
  - Greater relevance
  - Bridges between communities and agencies

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Kathleen McCarthy
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Bob Lynch
Community members
Community Advisory Boards
Tribal Advisory Council
Fishing Advisory Council
Study participants
Focus group members
Paul Barton
Chris Franks
OK Dept. of Wildlife Conservation
Brent Gordon
Grand River Dam Authority
Brent Davis
Darrell Townsend
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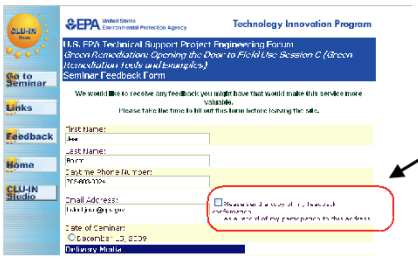
Resources & Feedback

- To view a complete list of resources for this seminar, please visit the **Additional Resources**
- Please complete the **Feedback Form** to help ensure events like this are offered in the future



Need confirmation of your participation today?

Fill out the feedback form and check box for confirmation email.

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