

**NATIONAL CONVERSATION ON PUBLIC HEALTH AND CHEMICAL EXPOSURES
EDUCATION AND COMMUNICATION WORK GROUP**

**Meeting Summary
November 12, 2009**

Meeting Objectives:

- Get to know each other
- Finalize the draft work group charge
- Learn about the status of the *National Conversation* process, project milestones, and the work group's role
- Begin describing what each target audience needs to know
- Identify tasks and task group membership
- Initiate survey of existing resources and programs in each task group
- Decide on next steps and assignments

Upcoming Meeting/Call	When & Where	Suggested Agenda Items
Full Work Group Call	Mid-January (TBD)	<ul style="list-style-type: none"> ○ Update on December 11 Leadership Council meeting ○ Progress check ○ Identify areas where NCEH/ATSDR project staff can assist work group
Public Sub-Group Call	Mid-December (TBD)	<ul style="list-style-type: none"> ○ Progress check
Health Professionals Sub-Group Call	TBD	<ul style="list-style-type: none"> ○ Prioritize and assign tasks ○ Progress check

I. Action Items

<i>National Conversation</i> Process Update and Milestones for the Work Group	Who	Completed by
1. Share idea of vetting community conversation toolkit through Pediatric Environmental Health Specialty Units with toolkit team	Jenny Van Skiver	December 4, 2009

Discussion of Draft Work Group Charge	Who	Completed by
2. Finalize draft charge based on full work group discussion	Kathy Rest Yanna Lambrinidou Marc Kusinitz John Stine John Sullivan Mary Lamielle	November 30, 2009 [DONE]

Tasks and Task Group Breakout Sessions	Who	Completed by
3. Schedule next full work group call	Dana Goodson	December 3, 2009
4. Choose a sub-group and commit to one or more tasks identified for that sub-group.	All work group members, particularly members not present at the November 12, 2009 meeting	December 4, 2009
5. Schedule next public sub-group call	Diana Degen	December 4, 2009 [DONE]
6. Schedule next health professionals sub-group call	Robert Washam	December 4, 2009

Work Group Membership	Who	Completed by
7. Consider whether there might be an industry gap on the work group, and, if so, how it might be filled	Kathy Rest, Jana Telfer, Dana Goodson, and Jenny Van Skiver	December 2, 2009

II. Agreements Reached

- The Education and Communication work group will operate under two sub-groups: a public sub-group and a health professionals audience sub-group. Tasks sub-groups. Bi-directional communication and learning will be addressed within the two sub-groups.

III. Call Summary

Welcome, Agenda Review, and Introductions

Following welcoming remarks by Dr. Kathleen Rest (Kathy), work group chair, and Jana Telfer, NCEH/ATSDR senior liaison, Dana Goodson, facilitator, reviewed the meeting agenda and ground rules. The group then participated in an activity to get to know one another and shared introductions around the room.

Some members felt that more industry representation was needed on the work group in order to ensure that the industry was involved and bought into the final work group product. Others questioned whether greater industry participation was necessary, given that there is already one industry member on the work group. The chair will take the comments under advisement and confer with the rest of the leadership and facilitation team on whether there is an industry gap on the work group and, if so, how it might be filled.

National Conversation Process Update and Milestones for the Work Group

Jenny Van Skiver, NCEH/ATSDR project staff, reviewed the “National Conversation on Public Health and Chemical Exposures: Milestones” document (Appendix A), identifying the Leadership Council, work groups, and the public as key project participants. Jenny explained that work groups will each

issue reports to the Leadership Council, and the Leadership Council will issue the final action agenda. Work group reports will be included in the final action agenda as appendices. Interested members of the public will be involved in the project through several public engagement mechanisms: a community conversation toolkit, web-based discussions, and public meetings. Public input will be fed into the work group process. The project timeline has been extended to April 2011.

Jenny emphasized the following major work group milestones:

- April – June 2010: Work groups to hold second in person meetings
- June 2010: Work groups to issue draft reports
- July – September 2010: Work groups to hold third in person meetings
- September 2010: Work groups to issue final reports to Leadership Council

Members asked questions for clarification on the Leadership Council, the action agenda, public outreach, and the community conversation toolkit. NCEH/ATSDR staff provided the following responses:

- The Leadership Council includes approximately 40 environmental and public health professionals. Names of the Leadership Council members are provided on the project Web site, accessible at http://www.atsdr.cdc.gov/nationalconversation/docs/leadership_council.pdf.
- The Leadership Council will not alter work group reports in any way; final work group reports will be included unedited as appendices to the action agenda. There is no guarantee that each recommendation made by each of the work groups will ultimately be included in the body of the Leadership Council's final action agenda.
- The project team has reached out to the public primarily through its partners and through its e-mail list of nearly 29,000 persons. The project team is interested in suggestions for enhancing public outreach.
- The Community Conversation Toolkit will include background information on National Conversation issues and process, a series of discussion questions, and a mechanism for reporting back to project staff. Staff will share input from the Toolkit with work groups.
- The draft Operating Procedures document sent to work group members by e-mail on November 11, 2009 outlines key process and role issues. Members should follow up with Ben Gerhardstein (bgerhardstein@cdc.gov) with any questions on the Operating Procedures.
- NCEH/ATSDR staff clarified that exposure to electromagnetic fields is beyond the scope of the project and that nanomaterials are within the scope of the project.

Discussion of Draft Work Group Charge

The version of the work group charge presented at this meeting reflected two rounds of revisions following the initial work group call on October 2, 2009. The most recent revision was the addition of point 3b, on reviewing current efforts of government and other important stakeholders to receive information and knowledge about public concerns about chemicals and health and recommending strategies and mechanisms for the public to better communicate their concerns to government agencies, health care providers, public and environmental health professionals, and other relevant institutions and actors.

Kathy Rest summarized that the three major components of the charge at this point were ensuring a well informed public, a competent network of health professionals, and two-way communication

between the public and government, health professionals, and other stakeholders. Members requested various language and substantive changes to the charge, including the following:

- Include prevention and solutions throughout the charge
- Incorporate point three (bi-directional communication) into both of the other sections (public audience and health professionals audience) instead of addressing it as a separate section
- Include specific language on health providers and professionals serving disadvantaged communities
- Define the terms in the charge
- Check with other groups to ensure we are not duplicating or missing key areas
- The word “concerns” in the charge comes across as patronizing; replace it with another word.

Based on the extensive comments, the members agreed that the charge needed more than minor editing. Kathy requested the assistance of a sub-group to finalize the draft charge following the meeting. Kathy Rest, Yanna Lambrinidou, Marc Kusinitz, John Stine, John Sullivan, and Mary Lamielle volunteered and will complete their revision over the next couple of weeks.

Brainstorming – What do the target audiences need to know?

The group completed a brainstorming exercise to consider the needs of target audiences. They considered the following questions:

1. What questions do members of the public frequently ask about chemical exposures and health?
2. What would you like the public to know or understand about chemical exposures and health?
3. What do you think health professionals should know or understand about chemical exposures?
4. What information do government agencies and health professionals need from the public in order to be effective in their work related to chemical exposures and health?

Members’ contributions to the four discussion questions are listed in Appendix B.

Tasks & Task Group Breakout Sessions

Kathy Rest proposed that the group might be most efficient if it divides into sub-groups. Members agreed to break into two sub-groups, divided by audience and incorporating multi-directional communication and learning within each group rather than as a separate sub-group. One sub-group was formed around the public, and the other was formed around health professionals. The full work group considered potential tasks the sub-groups might take on. Tasks were further discussed in the sub-group breakout sessions, summarized below.

Public Sub-Group Breakout Session

The public sub-group identified tasks and assigned responsibilities as follows:

Diana Degen agreed to serve as the Public Sub-Group co-chair.

Inventory Task Group

- Task: Inventory current and prior efforts of government and other stakeholders to communicate with and educate the public on public health and chemical exposure issues, noting gaps, inconsistencies, and evaluation components. Aim to create an exhaustive inventory and then select several examples with evaluations for analysis.
- Members: Elizabeth Grossman (task group lead), John Sullivan, Philip Wexler

Identification of Target Audiences and Definition of “well-informed public” Task Group

- Tasks:
 - (1) Identify target audiences within the public for which education and communication on public health and chemical exposure issues are most critical, and
 - (2) Characterize a “well-informed public.”
- Members: Cynthia Warrick (task group lead), Rosemary Ahtuanguaruak, Peter Dooley, Marc Kusnitz, Mary Lamielle, John Stine

Literature Review Task Group

- Task: Review both peer-reviewed and grey literature on issues relevant to communication and education about health and chemical exposures.
- Members: Alan Bookman (task group lead), Julia Brody, Elise Miller

Bi-Directional Learning/Communication Task Group

- Task: The group needs to flesh out its task but will aim to assess efforts for government and other stakeholders to receive information from the public.
- Members: Yanna Lambrinidou (task group lead), Diana Degen, John Stine, John Sullivan

Health Professionals Sub-Group Breakout Session

The health professionals sub-group identified tasks and assigned responsibilities as follows:

Robert Washam agreed to serve as the Health Professionals Sub-Group co-chair.

Tasks Identified

- Develop a specific list of target audiences (specialties)
- Conduct an inventory of professional association, NGO, and industry programs addressing chemicals or toxins
- Conduct an inventory of government resources available to support professional education
 - Leyla McCurdy and Amy Liebman will develop questions for government agencies on existing health professional education resources.
- Survey grey literature to identify relevant reports
- Conduct demographic analysis of target audiences to begin to understand preferences for receiving information/education
- Identify health professional competencies and practice guidelines and characterize as existing or lacking in current health professional network
- Create recommendations for clinical diagnostic tools and biomonitoring of exposures

Wrap-Up and Next Steps

Full Work Group

Dana Goodson confirmed with members present that Monday afternoons from 2:00 pm Eastern on and Tuesday afternoons from 2:30 pm Eastern on are generally good times for 90 minute calls. Dana will aim to schedule the next full work group call for mid-December; if this is not possible, she will schedule it for January. Dana also noted that the draft operating procedures state that missing three meetings will be considered resignation from the work group. Members were urged to send questions or comments on the operating procedures to Ben Gerhardstein.

A member asked that the topic of the legislative context be considered as a possible future presentation for a work group meeting or call.

Public Sub-Group

The public sub-group agreed to take less than two months to complete its initial products. Small task groups will begin work and the sub-group will hold a check-in call in mid-December.

Health Professionals Sub-Group

The health professionals sub-group will hold a call on assignments and next steps. Leyla McCurdy and Amy Liebman will begin developing questions for government agencies to learn about existing resources.

IV. Participation

Members Present:

Members

Rosemary Ahtuanguak, Inupiat Community of the Arctic Slope
Alan Bookman, New Jersey Department of Environmental Protection
Julia Brody, Silent Spring Institute
Stephanie Chalupka, Worcester State College
Alison Cohen, Brown University (*by phone*)
Diana Degen, The Cadmus Group, Inc.
Peter Dooley, Laborsafe
Elizabeth Grossman, Freelance writer
Marc Kusnitz, U.S. Food and Drug Administration
Yanna Lambrinidou, Parents for Nontoxic Alternatives
Mary Lamielle, National Center for Environmental Health Strategies (*by phone*)
Amy Liebman, Migrant Clinicians Network
Leyla McCurdy, National Environmental Education Foundation
Elise Miller, Collaborative on Health and the Environment (*by phone*)
Karen Miller, Huntington Breast Cancer Coalition/Prevention is the Cure, Inc.
Jerome Paulson, Mid-Atlantic Center for Children's Health and the Environment
Anne Rolfes, Louisiana Bucket Brigade
Matthew Stefanak, Mahoning County District Board of Health
John Stine, Minnesota Department of Health
John Sullivan, University of Texas Medical Branch/NIEHS Center in Environmental Toxicology
Susan Waldron, Ottawa County Health Department
Cynthia Warrick, Elizabeth City State University, School of Mathematics, Science and Technology
Robert Washam, Martin County Health Department
Philip Wexler, National Institutes of Health – National Library of Medicine

Members Not Present

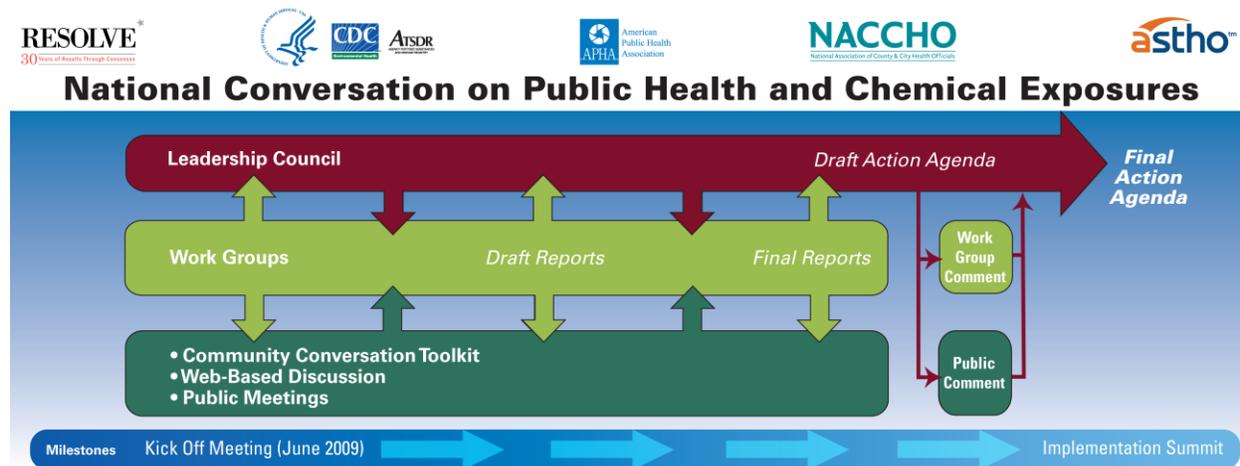
Jeffrey Jenkins, Oregon State University
Lena Jones, Jackson Roadmap to Health Equity Project
Debra Waldron, University of Iowa and Iowa Department of Public Health
Mark Wysong, IHS, Inc.
Lina Younes, U.S. Environmental Protection Agency

Facilitation & Staff Team:

Ben Gerhardstein, NCEH/ATSDR staff
Dana Goodson, RESOLVE facilitator
Kathleen Rest, chair
Jana Telfer, NCEH/ATSDR senior liaison
Jenny Van Skiver, NCEH/ATSDR staff

APPENDIX A. National Conversation on Public Health and Chemical Exposures: Milestones

DRAFT (11/9/09): For work group and Leadership Council consideration



Draft Milestones

Date	Activity
June – Sept 2009	<ul style="list-style-type: none"> Kick Off Meeting (June 26) Work Group Coordinating Committee begins to meet by phone Work group members selected
Oct – Dec 2009	<ul style="list-style-type: none"> Work groups begin to meet by phone Work groups hold in person meetings (Nov 12 – 17) First Leadership Council meeting (Dec 11) Project team and other partners begins holding public meetings to engage key stakeholders (meetings to occur periodically throughout remainder of project)
Jan – March 2010	<ul style="list-style-type: none"> Project team launches Community Conversation Toolkit (community meetings to occur throughout remainder of project) Project team launches web-discussion platform (web-discussions to occur periodically throughout remainder of project)
April – June 2010	<ul style="list-style-type: none"> Work groups hold second in person meetings Work groups issue draft reports (due June 2010)
July – Sept 2010	<ul style="list-style-type: none"> Leadership Council holds second in person meeting Work groups receive comments on draft reports Work groups hold third in person meeting Work group issue final reports to Leadership Council (due Sept 2010)
Oct – Dec 2010	<ul style="list-style-type: none"> Leadership Council holds third in person meeting and develops draft action agenda (due Dec 2010)
Jan – April 2011	<ul style="list-style-type: none"> Leadership Council receives comments on draft action agenda Leadership Council issues final action agenda (due by April 2011) Implementation Summit

APPENDIX B. Brainstorming Session Results

1. What questions do members of the public frequently ask about chemical exposures and health?

Theme: *Responsibility, Accountability, and Trust*

- Who did this/caused this?
- When did you know about this/How long has this been going on?
- What are you hiding?
- Who's going to fix it/treat it/clean it up/help us?
- Can I get compensation?
- Who will buy me out so I can move?
- What else do you know that you're not telling us?
- Why did your study conclude that we need another study?
- How do you know this level is safe?
- How are levels set?
- Why was this product allowed to be sold?
- We've been going to clinic with these problems; why haven't we gotten help?
- Who's profiting from this?
- How do we know we can trust you?
- What is the time table for resolving the problem?
- Who's responsible and who will pay?
- Can this happen again?
- Somebody is screwing us and will get away with it.
- Why did government let this happen?
- Why should I trust you? The investigators/monitors work for the industry (work place).

Theme: *What does this mean?*

- What are long term consequences?
- What are the chemicals, and which should I be concerned about?
- What does it do to me and future generations?
- What is my exposure right now?
- Why does my community have all these problems?
- Is this safe?/Is there any safe level?
- Where is it going, and what is it doing to our food?
- What about unknown impacts?
- Why can't experts agree?
- What are reproductive effects?
- Are there special age effects?
- What's the answer?
- How does it affect my pets?
- How widespread are other communities affected? Are there interactions with other factors/exposures?
- What is the full range of health effects from this chemical?
- Does it cause cancer? Developmental delays?
- How will this impact our health/my children's health/pets' health/wildlife?
- How long will exposure be there?
- How does it affect my property values?
- Am I safe in my home?
- Are my symptoms related to the chemical?

- I've lived here forever and my family/parents are okay. (denial)
- Why does this matter now?
- What is the precautionary approach?
- I have made up my mind.
- Am I sick from "x"?
- What can I eat/drink/do to protect myself from "x"? What should I do to avoid the risks?
- What are impacts from building materials? Vaccines?
- How do I stay healthy?

Theme: *Resources*

- What are my rights?
- Where can I go for help?
- Where can I get this product tested for safety?
- Is there a treatment/how can I get it?
- Where can I get information?
- Can we use information to change policies?
- What are the ingredients in consumer products? Where is this information?
- Who can I report things to without retaliation (work place)?
- I don't know enough to ask a question.

2. What would you like the public to know or understand about chemical exposures and health?

Theme: *Scientific Understanding*

- How exposure affects/would affect them
- What constitutes "exposure" - basic concepts and definitions
- Know potential health effects and solutions
- Challenges/limitations in documenting cause and effect; understanding complexity
- Level/degree of scientific uncertainty (example tobacco smoke)
- Difference between chronic/acute exposure
- Different populations (example-children) are affected differently.
- Genetics and underlying health conditions can play a role in susceptibility
- Scientists are revising how think about low doses
- When exposure has occurred/how to minimize risk
- Scientific research is rarely conclusive -significant variability, unknowns, uncertainties
- Results of national exposure report
- Natural is not always good/Synthetic is not always bad.
- People are exposed to chemical mixtures but studies are chemical by chemical
- Scientists are rethinking timing of exposure and effects - Chemical exposures, even minute doses during fetal development through adolescence at certain critical windows, can have lifelong health implications.
- Elevating knowledge about chemicals can be a springboard to other achievements.
- Physical signs of exposure to different chemicals (chronic or acute)
- We're all exposed to chemicals.
- Some chemical exposures are beneficial.
- Many everyday exposures can harm them or their children and other susceptible populations
- More is not (usually) better.
- We're affected by a combination of chemicals and toxic exposures.
- Connection between your health and chemical exposures.

- We're always exposed to background levels of chemicals.
- Women of child bearing age and children are particularly vulnerable.

Theme: *Understanding and Navigating the System*

- How to access "the system" for corrective action
- Regulatory system does not necessarily protect
- What agencies to call when an issue arises; where to find the phone number
- How to utilize media; how to work within /around the system
- Government/regulators cannot fix everything for you
- What to do if they are exposed
- Where to go for help and information by venue
- Regulatory system does not use precautionary approach
- We are investing more in medical research/care than in prevention.
- Healthcare provider doesn't have clinical/ diagnostic tools for exposure
- Health providers have limited training in environmental and occupational health
- Chemicals in consumer products don't have to be tested for health before put into use; most aren't.
- Other regulatory systems may provide best practice examples.
- Ultimately we can't buy our way out of this situation, but need to press for stronger chemical policies and regulations and for companies to develop safer alternatives.
- Examples of successes (example lead/gasoline; smoking in public; Clean Air Act)
- The conversation about "green" is more about energy than health.

Theme: *Personal Action*

- How to prevent/mitigate exposure
- Purchasing decisions can result in harmful exposures for environmental consequences to themselves and to others.
- Impact of purchasing decisions on other/world
- If your health changes ask questions; continue to do so.
- Develop community leader to become peer trainers [COS H model]
- Demand help from healthcare providers
- Science is slow; public cannot wait for the science to take precautionary steps
- There are safer alternatives, many of which are not more expensive.
- Sense-making skills – build decision-making skills
- Feel safe to participate
- Public are consumers therefore power lies with them.
- Know how to have conversation with healthcare provider; limitations of healthcare provider; where to go for (best) help
- Some adverse exposures can be reduced/modified by personal practices
- Must be active to get action – work the legislative system/be proactive
- Be proactive/alert even though the condition may not affect them their family personally (example if no family history)
- When/why to take action in the absence of absolute proof
- Conventional pesticides are poisons. Proceed with caution. Less toxic alternatives are generally available to address a problem. Some insect are unaffected by poisons—vacuum the spiders, don't try to kill them with chemicals, etc. Lawn care pesticides are toxic and unhealthy for all.
- Small changes in lifestyle can have a significant impact on everyday health and well-being—no smoking, no fragrances or fragranced products, etc.

- It's not hopeless.
3. What do you think health professionals should know or understand about chemical exposures?

Theme: *Scientific Understanding*

- How exposure relates to overall health
- All the ways it could be affecting patients
- Windows of vulnerability
- Environmental Health 101, particularly on exposure pathways
- Mixtures of chemical exposures
- There are multiple causes and effects and cumulative and additive effects.
- Awareness that disease could be related to exposure
- They already know that large-scale exposures could cause overt symptoms/death but don't know that low dose and long term exposures can have adverse outcomes.
- Importance of timing (different life points)
- How to assess for chemical exposures (medical education on tools, etc)
- We study chemicals with clinical trials; we need to use other evidence.
- Lifestyles can exacerbate effects.
- Have awareness of patient exposures, cumulative risk, multiple stressors
- Understand disenfranchised communities are disproportionately exposed
- Understand kids; vulnerable populations
- Signs and symptoms
- To be able to identify a sentinel event
- Relationship between environmental exposures and ADHD
- Healthcare is not "one size fits all"
- Understand how to create healthy indoor environments in offices (e.g. furnishings, and operations and maintenance practices including tobacco, pesticide and fragrance-free policies and practices, least toxic cleaning agents, no air fresheners, deodorizers, etc.)

Theme: *Situational and Local Awareness*

- Community level – what type of exposures some have as opposed to others (example proximity to toxic sites)
- Better understanding of places people exposed
- Local, traditional, historical knowledge
- How you live, what eat important
- Understand environmental justice
- Stay informed on local contamination events
- How to be alert to events and what to do
- Controls that should be in place – what could be done to fix problem (example work place exposure to solvents)

Theme: *Resources*

- Who to report to?
- Information on referrals
- Collaborate with local state health departments on data collection
- Awareness of professionals with expertise on chemical exposures and risk
- Where to go for information

- Identify champions in the medical field

Theme: *Patient Interactions*

- Environmental history – incorporate into health history. How can health professionals do this comfortably?
- Understand the immediate need for answers from those exposed
- Skills for saying “We don’t know.”
- Take on a bigger role beyond patient care – reporting responsibility; be an advocate.
- Provide counseling on prevention and risk reduction, anticipatory guidance
- Advise people on how to seek additional information and support
- List of resources to share with patients
- Patients affected by low level chemical exposures should not be ridiculed or disparaged or refused assessment or treatment by medical professionals. Discrimination is against the law. Honesty in admitting one doesn’t understand is not.
- Understand that some patients may not be able to access indoor environments or may need disability accommodations to secure medical or healthcare.
- Some patients who have severe sensitivities/intolerances to everyday chemical exposures are not getting appropriate or adequate healthcare even when faced with a very treatable condition, and they suffer the consequences of failure of the medical community to be equipped to address these individuals.

4. What information do government agencies and health professionals need from the public in order to be effective in their work related to chemical exposures and health?

Theme: *Data*

- Government needs data on adverse exposures/health outcomes
- The public has historical information - including medical history and stories, which are often better indicators than hard data.
- Data from workers
- Health professionals need data/stories from individuals to build public into environmental health tracking and share information.
- Workplace exposure information- identify of products/chemical information – MSDS sheets need to be understood
- Government needs independent (not self-reported) data
- Community-based research

Theme: *Infrastructure to Act*

- Health care providers/professionals need someone to tell when potential environmental health issues arise.
- A more open line of communication between public (patients) and health care providers and between public and government
- Trust
- Government needs to define for the public what information they need to be able to take action.
- Government agencies and health professionals need to be open and receptive.

Theme: *Situational and Local Awareness*

- The cumulative risk burden in the community they are working in
- Public's prior experience
- Big picture – Look at economic (jobs) and social considerations; how do environmental health issues fit in?
- Which parties are involved?
- Who are leaders in the community? Who is trusted and has time? Who has actual power?
- Cultural perceptions of causes (of health outcomes) and cultural barriers
- What is the public worried about?
- Health professionals should have knowledge of facilities releasing/using chemicals nearby
- Activities people are undertaking that might result in exposure

Public Knowledge

- Public perception of risk they face
- Changes in their community
- Parents should be vocal about concerns regarding their children
- Where public gets information – public needs to note and share with government /health care providers
- Local knowledge of exposure pathways, routes of exposure/health resources/ health effects/ individual and community histories
- Public input on criteria for data and processes
- How public wants funding to be directed (What public programs do they want?)
- Information on environments people are exposed to (public to report)