California Environmental Health Tracking Program

Issues in Stakeholder Participation and Risk Communication: Lessons Learned from the Alameda County Pilot Project

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Why stakeholder participation?

- Participation is essential for determining:
  - Information and tracking needs of CBOs, NGOs, local agencies, and others
  - Appropriate methods for presenting and disseminating information
  - Training and technical assistance needs
  - Potential uses of tracking to further community goals, promote EJ, and improve public health

- Participation is also key for gaining recognition, support, and partnerships for program activities
Disparate sources of data

- coordinate between agencies
- develop IT infrastructure
- format and process data

Useable datasets

- tabulation
- statistical analysis
- map making

Results

* Key point for stakeholder input
- develop and field test materials
- create mechanisms for access and dissemination

Information for action
Alameda County Pilot Project

- **Alameda County**
  - 1.4 million residents
  - Culturally diverse population with range in socioeconomic status
  - Many communities with a history of social and environmental activism

- **Scope of project**
  - Birth outcomes
  - Asthma
  - Traffic pollution
Know your stakeholders

- Who are they?
- What are their concerns
- How do they want to be involved?
Identifying and getting to know our stakeholders

“It would be good for you to be chased out of the neighborhood by dogs”

- Barriers to getting participation by communities in Alameda County
  - Historical distrust of government and other outsiders
  - Previously left empty-handed by researchers
  - Limited time and resources to offer
  - Differences in communication styles and backgrounds may complicate understanding about the project- logistics, benefits, etc.
How to address these barriers?

- **Persistence**

- **Introduction through NGO intermediary**
  - Provided entry into new communities
  - Moderated/facilitated discussions
  - Provided insight into relationships, histories, concerns

- **Put in time, help out, & give them something upfront**
  - Demonstrated commitment and competence
  - Established rapport
  - Identified other key players
  - Identified and improved understanding of key issues, concerns, and mechanisms for involvement
  - Identified community assets/potential collaborators

→ need program support to do this!

“You’re not with the government. You’re with the community”
Recruiting participants

- **Getting the right people on our list**
  - Knew what we wanted to get out of this process
  - Knew who should be involved in the process
  - Asked for suggestions from NGO and CBO partners
  - Identified stakeholders through our work with community

- **Explaining the project and the participation process**
  - Developed materials specific to stakeholder interests
  - Contacted by phone calls, letters, e-mails
  - Used partnerships and referrals

- **Getting them to come**
  - Explained potential benefits of project and participation
  - Upfront about time commitment, roles and responsibilities
  - Provided stipends, transportation reimbursements, food
  - Lots of follow-up
Who’d we get?

- Representatives from ~ 25 organizations including
  - Community-based organizations
  - Non-governmental organizations
    - Environment
    - Health
    - Urban planning
    - Social Justice
  - Local environmental and health agencies
  - City council offices
  - Health care/ service providers
  - EPA
Facilitate meaningful involvement

- Involve them early
- Make it easy for them
- Strive for win-win situations
Our stakeholder participation process

- Facilitate at least 5 quarterly stakeholder meetings planned to coincide with completion of specific analyses
  - Intro to tracking and birth outcomes findings *(Jan 04)*
  - Asthma findings *(May 04)*
  - Traffic pollution findings *(Sept 04)*

- Dissemination plan and policy implications
  - Associations
  - Wrap-up and next steps

- E-mail/postal mail updates and follow-ups
Planning and facilitating meetings

- **Partnership with NGO**
  - Provided assistance in planning and facilitation
  - Offered experience, insight, alternative point of view
  - Trusted by / familiar to many stakeholders

- **Weeks (or months) of planning**
  - Involved NGO partners and a range of project staff
  - Determined program and stakeholder objectives
  - Considered background, expectations, interests of a diverse group
  - Planned agenda, activities, and materials accordingly
  - Reviewed, revised, and practiced presentations
    - Content
    - Language and tone
    - Comprehensibility
  - Used feedback from meeting and evaluations to improve future meetings
General meeting structure

- Introductions
- Overview /recap/updates
- Background on project subject area
- Discussion about needs, activities, and concerns
- Presentation of methods and findings
- Input and feedback on findings
- Dissemination plan
- Next steps
Obtaining useful input

- Discussed information in a way that was
  - Clear and comprehensible
  - Focused on aspects most relevant/interesting to the group

- Openly addressed all aspects of the project
  - background, strengths and limitations of data sources and methods used, significance of findings, project status, etc.

- Gave them the information they needed to be able to provide useful and honest feedback

- Developed targeted activities to solicit information
Obtaining useful input

- Planned time for and facilitated open-ended discussions
- Created decision-making opportunities
- Managed expectations by being honest and upfront about our objectives and abilities
- We are using stakeholder input to guide how we:
  - Analyze, present, and disseminate data
  - Identify partners and opportunities for collaborations
  - Plan future meetings
  - Plan a tracking network
Respond to stakeholder concerns

- Anticipate
- Prepare
- Practice
What we’ve heard about

- Stakeholder concerns, activities, and information needs
  - barriers to accessing and using information
  - uses of information

- Reactions to tracking (program and concept)

- Needs and activities around project areas

- Reactions to tracking findings
  - Does this make sense?
  - Interesting? What’s new?
  - Useful? For what?
  - What would make this more useful?
  - Suggestions for changes?
  - Concerns?
Issues in communicating tracking information

- Stakeholders want data that is useful
  - community level
  - data on affected communities
  - compared to social and economic data
  - cost-benefit analyses
  - temporal and spatial analyses
  - identification of hot spots
  - data for range of exposures and outcomes
Issues in communicating tracking information

- **Stakeholders want to understand the data**
  - Benefits and limitations of data sources and samples
    - Non-representative sample size
    - Small sample size
  - Association vs. causation
  - Statistical significance
  - What can you say about these findings
  - Supplemental information
    - Activities for prevention
    - Policy issues
Issues in communicating tracking information

- Stakeholders want to access and use the data
  - Digital divide in some communities/populations
  - Language - lay, technical, non-English
  - Technical assistance
  - Capacity building
  - Information in a range of formats including hard copy, websites, presentations by staff
Prioritizing

*With one year left and limited staff time, resources, and expertise, stakeholder group needed to prioritize materials and dissemination activities*

- Created example materials for stakeholders to react to - fact sheets, brochures, GIS website
- Asked our stakeholders for recommendations and priorities in context of the pilot project status, staff resources, timeline
- Explored internal and external resources
Group priorities for dissemination plan

- Prioritize making information available on the Internet
  - interactive GIS interface
  - downloadable maps/tables

- Provide many options for maps (e.g. smoothed maps, maps with rates by census tract). These can be used to create materials tailored to specific audiences

- Add interpretive narrative to maps / create modules that will help with using the information

“It is your job to provide the data. It’s our job to make sure it gets used”
The dissemination plan

- Partnership with InfoOakland to develop an interactive GIS interface that displays our data (www.infooakland.org)
  - Expertise and experience
  - Mission and stakeholders match
  - Technical assistance, capacity building
  - Responds to stakeholder interest in socioeconomic, demographic, and urban planning data
  - They will host maps, tables, narratives, caveats, etc. based on our guidelines
  - Link to our site
The dissemination plan

- Our website will contain “popular maps” and modules
  - Background information on exposure or outcome
  - What this map/table/chart is showing (interpretation)
  - What does this say/doesn’t say (caveats)
  - What actions have been taken previously with this type of information (how this information might be used)
  - Additional resources

- List resources and contact information for questions, technical assistance, requests for us to do presentations

- Modules will be written in lay language, but may add links to technical interpretations and explanation of methods
What about other stakeholders?

- We are facilitating a stakeholder process that we hope will be useful to a representative group of participants.

- This participatory stakeholder process will be used to anticipate and develop an education and dissemination strategy that we hope will be responsive to the broader stakeholder audience.
What about our other pilot project?

→ Central Valley/South Coast Pilot Project

- Where?
  - Central Valley and South Coast air basins

- What?
  - Airborne hazards (including pesticides)
  - Maternal and infant blood levels
  - Birth outcomes
  - Sudden Infant Death Syndrome (SIDS)
  - Autism Spectrum Disorder
  - Mental Retardation
New considerations

- Larger geographic area covered - urban and rural

- Combined population of ~ 20.6 million

- Special populations to consider (farm workers, affected children)

- Sensitive and politically-charged health outcomes

- Hot spots for less common outcomes may not be detectable

- Connections between some health outcomes and hazards are less well defined (compared to Alameda County project)
Difference in scope requires new approach

- **Recruiting stakeholders to the project advisory team**
  - Cannot do community-level work, in-person interactions to the same degree
  - Use partners’ networks—must be sensitive to their relationships
  - Use advisory team to identify additional stakeholders

- **How to involve all the stakeholders**
  - Multi-tiered stakeholder involvement approach
  - Select advisory team members who are respected and well-connected
  - Advisory team must have more active role in guiding this project—key in engaging the larger stakeholder audience and conducting project in culturally/politically appropriate manner

- **Use a professional consultant to facilitate and evaluate**
  - Experienced working with a diverse group, impartial
Stakeholder participation process: lessons learned

- Partnerships and collaborations were essential
- Supportive and engaged program staff were a foundation for establishing and facilitating this process
- Persistence, time, and effort paid off

- Diverse stakeholder group was able to engage with the process and the findings in a thoughtful and sophisticated manner

- In general, stakeholders appear supportive and some have voiced the desire to support tracking, to advance policy, continue discussions, and become more involved in overall effort

- Even though a tracking system is not in place, some stakeholders have said that the process, knowledge gained, and relationships developed with us has been worthwhile in themselves
Communicating tracking information: lessons learned

- Communicating tracking information involves discussing information needs, presentation, accessibility, usability

- Communicating about project background, data sets, methods to a broad stakeholder group in a comprehensible fashion is possible and a good idea

- Participatory process helped the group to understand and trust methods we used and our judgment regarding the findings: they would like to know and for us to tell them strengths, limitations, and caveats with our findings
Issues we still need to address…

- How should we evaluate the effectiveness of our participation and communication strategies? Is this really working?

- What are the best ways to describe/explain methods, strengths, limitations, caveats of tracking data and a tracking system?

- Is our communication/dissemination strategy possible on a large scale?
  - How to expand statewide while keeping the community-level specificity?
  - At what point does it become too large to be useful?
  - What kinds of resources/staffing/partnerships would it take to sustain this?

- What kinds of barriers will we run into regarding state-level approval for this communication/dissemination plan?

- What should be the process for involving stakeholders if this is expanded and extended?

- Will the info really be used? How do we prevent misuse/misinterpretation of data, particularly by those who actually intend to do so?
# Thank you

## Centers for Disease Control and Prevention

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<tr>
<th>University of California Center of Excellence for Environmental Public Health Tracking</th>
<th>California Environmental Protection Agency (Cal/EPA)</th>
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## Collaborators:

- Alameda County Pilot Project
  - InfoOakland
- Pacific Institute for Studies in Development, Environment, and Security
- Kaiser Permanente of Northern California

## Collaborators:

- CVSC Pilot Project
  - California Air Resources Board, Cal/EPA
  - Childhood Lead Poisoning Prevention Branch (CLPPB), CA DHS
  - California Center of Excellence for Autism and Developmental Disabilities Research and Epidemiology (CADDRE)
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