

The following table is a synopsis of the small group discussions of the California Environmental Health Tracking Program’s Planning Consortium (From the Third Meeting: Oct 23, 2003) regarding the SB702 Draft Report. Members were asked to discuss the relevancy of the recommendations to their organization/efforts, factual concerns, and what’s missing. The Planning Consortium members were segmented into NGO and Public Agency groups for various reasons including: (1) attempting to capture information/feedback that was unique to each sector; (2) facilitating/promoting a more open discussion without apprehension or reservation.

Non-Governmental Organizations	Public Agencies
<b>Relevancy:</b>	
<ul style="list-style-type: none"> <li>• Many NGOs are involved in raising public awareness – Tracking can be important tool in that effort.</li> <li>• The report itself will help to raise awareness of and describe the complexity of data linkage.</li> <li>• The report is relevant in that it touches on what Tracking can and cannot do.</li> <li>• Data access barriers currently exist. NGOs need easy (centralized) access to environmental and health data.</li> <li>• Environmental Health Tracking adds to what NGOs working in Biomonitoring need.</li> <li>• Tracking is relevant in that it can be a tool to reduce or get rid of chemicals/toxins in the environment.</li> <li>• The report is relevant to the extent that it discusses the importance to identifying the distribution of hazards and diseases. That alone is important to organizations. Linkage and hypothesis testing are important goals but PC members recognize the scientific challenges establishing causality.</li> </ul>	<ul style="list-style-type: none"> <li>• Executive summary should indicate which government and NGO agencies should be brought into the planning for this effort.</li> <li>• Section on cluster investigations-Finding 7, before the recommendation. The language sounds like the group is promoting cluster combing. Should clarify if that is not what they mean to say. To say that cluster investigations should only occur if the etiology of the disease is known does not sound realistic. (Jennifer Mann will send in her concerns on this).</li> </ul>
<b>Factual:</b>	
	<ul style="list-style-type: none"> <li>• Registry of rep sample is strange (need to either recommend a sample or a registry) make clear.</li> <li>• “Representative proportion of the population”—same issue.</li> <li>• P. 146 Finding 8 “Tenant” should be “tenet”—spell check missed this.</li> </ul>
<b>What’s Missing</b>	
<ul style="list-style-type: none"> <li>• Ensure that the report describes community/public input and involvement processes. How will the state agencies be accountable to the public? Will there be an appeals process to findings/decisions by the state agencies? The roles for the communities must be clarified.</li> <li>• Need to collect long-term data on multiple hazards; timing.</li> <li>• There need to be a process to critique/evaluation process where users can feed back on network utility. User friendly information is critical.</li> <li>• Active surveillance system to “flag” potential problems. In other words, the system should alert the public of “hot spots” of hazards/diseases. In</li> </ul>	<ul style="list-style-type: none"> <li>• Advisory body should include industry, labor and Tribes.</li> <li>• Put the prevention message UP FRONT as a fundamental rationale for tracking.</li> <li>• Will Tracking be sensitive and specific enough? Similar to NGO data quality issue.</li> <li>• Agencies outside of DHS/CalEPA how can they use Tracking to support their agency goals / evaluation. <b>Need to include in Exec Summary.</b></li> <li>• Not enough information about roles/relationships of advisory bodies. Specifically the Science Advisory Body.</li> <li>• Privacy issues are not well developed.</li> </ul>

<p>such cases, a “rapid response team” should be deployed to address the situation.</p> <ul style="list-style-type: none"> <li>• Report should address how to better track time and length of exposure, long term exposure, combined/multiple exposure, and migration.</li> <li>• Report should emphasize easier access to data.</li> <li>• Report should address the accuracy, sufficiency, assumptions, limitations, etc. of data mentioned in the report. Not addressing said caveats or misuse of data can lead to distrust from communities. There needs to be mechanism to ensure data quality and be clear on the “truth” about existing data.</li> <li>• The data caveats must be explained/described in a language people can understand.</li> <li>• Need to consider/address data quality objectives or minimum standards.</li> <li>• Need to involve stakeholders at various stages of planning, implementation, and maintenance.</li> <li>• The report should describe (or call for studying) the feasibility/utility of other data sources, not necessarily statewide or on-going. There is a wealth of data being collected by Universities and organizations such as Pesticide Action Network of North America (PANNA). Report should also address ways to gather/share community generated data.</li> <li>• The report should address “upstream issues” or “driving forces” in addition to the hazards/diseases.</li> <li>• The proposed Tracking system should go beyond a mere “clearinghouse” of information role. The state agencies must ensure that the information is understandable and useable. They must make an effort to get data/information to where people live. They must get information out to the communities in public forums and town-hall type of setting.</li> <li>• Recommendations #2 and #8 needs to be better bridged.</li> </ul>	<ul style="list-style-type: none"> <li>• Where are the doctors; what are the roles of the medical community? Explain why we don’t have a reporter-based surveillance system, why wouldn’t we want one? The public may ask why the EWG did not recommend this.</li> <li>• Access to health care may impact quality of data; recognize that hospital discharge provides incomplete picture.</li> <li>• List data gaps up front in the document (maybe under the “why track?” section of the Executive Summary).</li> <li>• Role of Health Department as an unbiased source of information; community trust and data issues.</li> </ul>
<b>Consensus</b>	
<ul style="list-style-type: none"> <li>• There is general support from NGOs with the caveat that the above issues and concerns be addressed in the final document.</li> </ul>	
<b>Needs more Emphasis?</b>	
<ul style="list-style-type: none"> <li>• Data access / clearing house that provides “one-stop shopping.”</li> <li>• Right-to-Access and Understand data.</li> <li>• Make sure rapid response team / mechanism is clear, well articulated, and complete.</li> <li>• Advisory committee with town-hall function, capacity.</li> </ul>	<ul style="list-style-type: none"> <li>• Right-to-Know / Right-to-Access and Understand data. May require information distribution that is not on INTERNET. Determine best methods of health information access; evaluate best communication methods.</li> <li>• Prevention message defined up front as the major driver for doing Tracking.</li> <li>• Formatting issues; findings vs. recommendations need to be clear; recommendations <b>do not jump out</b>; (see Women’s Foundation Report).</li> <li>• Highlight privacy issues in chapter 8 / exec summary.</li> </ul>

Report Format	
<ul style="list-style-type: none"> <li>• Cal/EPA recommendations need to be better linked to Environmental Health Tracking. Integrate Cal/EPA EJ recommendations into chapter 8.</li> </ul>	<ul style="list-style-type: none"> <li>• Wording is not consistent: some Findings in chapter 8 still sound like recommendations. Finding #2 in Chapter 8 is a recommendation and a finding. Make language consistent.</li> <li>• Recommendations need to be highlighted in the executive summary so they will <b>stand out</b>.</li> </ul>
Broad Issues	
<ul style="list-style-type: none"> <li>• Funding &amp; sustainability issues.</li> </ul>	<ul style="list-style-type: none"> <li>• Web-based information could worsen the disparity issues (See OPR EJ Report for guidance) Ensure that information is provided at the library via the web, but much more is needed).</li> <li>• Will Tracking be sensitive/specific in terms of capturing sub-acute conditions or low level exposures?</li> </ul>

**Large Group Discussion:**

- Emphasize the importance of looking at trends for precautionary action.
- Acknowledge that there are limitations in the current data.
- Discuss data access issues for communities lacking in resources (e.g. tech divide).
- Foster community ownership of tracking.
- Health communication efforts are essential- specifically, state should fund these positions.
- Discuss trust issue: people may not trust the government or industry for health information, this may be a possible reason for limited health education funding at the state level. People trust NGO's and doctors more than government and industry. People trust women more than men. You can engender trust by providing truthful, correct information.
- State public health in fact is one of the more unbiased sources of information because it meant to serve the public and all employees must sign a conflict of interest statement. This is different from other groups such as doctors and academics that may have conflict of interest issues.
- It adds validity to the report that it is an unbiased effort by the state. This should be noted explicitly in the report.
- The outreach and education team should discuss this trust issue at some point.
- The Governor's Office of Planning has created EJ recommendations that should inform the report.
- The PC members may be able to cite other sources of information besides those currently mentioned in the database list.
- The tracking effort will itself increase awareness around environmental health issues.
- CBO's may use tracking beyond policy advocacy and education (e.g. marketing campaigns).
- It is important that the CDC and the Expert Working Group hear this valuable input.