

**Comments on Review Draft of the
Report of the Expert Working Group on Environmental Health Surveillance
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Note: these comments present the views of the author and not any institution with which she may be affiliated.

A. Overall Comments

The report as a whole is very impressive, particularly in the specific discussion of needs with regard to disease tracking. This represents perhaps the most specific and informative discussion of these issues available to date. The nuanced and thoughtful discussion of community interests and needs is also excellent and innovative (though I would imagine that quite a few comments will be made about the specifics.) The goals for the program are also well considered and I think would be a good set for the national effort to adopt.

B. Executive Summary

The recommendations stated in this section do not seem to be the same as those in the later chapter showing findings and recommendations. It is not clear which is the more current version, so comments are provided on both. This section discusses recommendations as stated in the executive summary.

Data Clearinghouse

The idea of a central clearinghouse that would set priorities for data collection seems rather far-fetched. There are many competing mandates and needs for data, not the greatest one of which would necessarily be the tracking initiative. It might be more fruitful to have a clearinghouse focus on finding ways to make data more accessible and sharable. A more collaborative approach to deciding data collection priorities might ultimately work better. A key priority is to provide for data access. This is probably more critical for data held by the Department of Health Services than for that held by the California Environmental Protection Agency, which has had historically had more of a commitment to data release.

Confidentiality

The second recommendation says that data should be provided in a summary format to protect confidentiality. The recommendation should be revised to say that the means used for data dissemination protect confidentiality. This may require providing summaries in some cases but may not in others. Data access should be limited only to the extent necessary to protect confidentiality.

Need for resources

In the third finding, it would seem that something might be said about the need to fund the essential infrastructure. It takes more than leadership.

Cumulative hazards

In the fourth finding, there is a mention of the need to provide information about cumulative hazard data at the community level. Such data needs to be made available at the community level, the regional level, and the state level. Moreover, methods for this need to be developed.

New surveys and systems

Several recommendations talk about developing California versions of national data programs (including NHIS, NHANES, etc.) Because there is also a nationwide component to tracking, it might be appropriate to consider whether some of the existing national data collection efforts could be augmented to address California needs at less cost and with greater consistency with national numbers. It does not appear that this was considered by the expert panel. One critical concern for survey approaches, as noted elsewhere, is response rate, and it appears that some of the national initiatives achieve better response rates than state level analogues.

Clusters

The finding about clusters seems to be rather confused. One issue is to define whether an observation of a number of disease cases is a cluster (or not). This needs to be addressed independent of what you think the etiology might be. This does not seem to be addressed in this draft, here or elsewhere. The finding has a broader title than the text, and it would seem that this might be divided into two parts, because the cluster related issues may or may not be the ones that communities are most interested in. (The description of community projects and concerns later in the document would suggest not).

Disparities

In the finding on gaps by race/ethnicity, the text says that such gaps need to be continually monitored. They also need to be identified. Data about this are severely limited. Both disparities in exposures and outcomes are relevant.

Implementation

I think it would be good to include more of a call to action at the end of the executive summary. Now it ends rather abruptly and is not clear about what the critical next steps are and who needs to do what. Whose responsibility is it to start to address all the many issues and needs that have been identified?

C. Mayor Comments

1. Definition of “hazard”

Though it is consistent with some standard references, I think that the way the group uses the term “hazard” is confusing. “Hazard” is used to refer to any environmental agent or factor that might be included in tracking, presumably on the theory that we would only track things that we know or think are hazards. The issue, of

course, is that it isn't that easy to know what exactly does pose a hazard, and we may need to do some tracking and investigation to find this out. This issue also arises when discussing different kinds of data sources. Some data about "hazards" is about concentrations of environmental agents in environmental or exposure media. Some data about "hazards" is about usage or release of environmental agents. Whether such agents ultimately become "hazards" or not can be hard to say. In all likelihood, some part of what is released will pose a hazard to some, and some part will not. All of these issues need to be sorted out in the design of the system, selection of agents for tracking, identification of the most informative venue(s) in which to measure or estimate concentration of agents, etc. But subsuming all of this under the term "hazard tracking" is conceptually confused.

For example, at page 19, you say that environmental hazards are chemical, physical agents, biomechanical stressors or biological toxins that are present in the environment and that have negative impacts on human health. How do you know for sure which agents have a negative impact on human health or which releases of such agents are relevant? Are you saying that only those agents for which such relationships are well established would be included in tracking?

This issue also arises at page 21 in the third full paragraph where it talks about concentrations of "hazards." Well, what is a hazard depends in part on the concentration, doesn't it? This would all be more straightforward if the term "agent" or "factor" was used rather than "hazard."

The question of what is the best way to measure exposure also seems to deserve more thought. The report seems to assume that measurements of agents (or hazards) in human samples are always the best way to determine exposure. However, this is not the case. For compounds that are rapidly metabolized or excreted, a measurement at any point of time may not provide a useful estimate of exposure, and it may be more informative to measure the chemical in the exposure medium instead. It might be useful to include some discussion of what types of compounds are best measured through biomonitoring and what may not be.

2. Public Perception

I like the presentation about the public perception of environmental health risks. It provides an interesting perspective.

3. Prevention

The discussion of tracking to guide prevention strategies (at page 36) seems a bit abbreviated and might benefit from consideration of examples in addition to lead.

The case study about lead in gasoline is interesting, though I would draw a different conclusion from it than you did. The scientific knowledge to justify removal of lead from gasoline was available for many years before any action was taken. I do not believe that it is correct to argue that any sort of tracking system was needed to scientifically justify this. Moreover, some "model-based analyses" predicted the reductions in blood lead levels that were achieved. In another example, Kate Mahaffey's model-based predictions of blood mercury levels turned out to be very accurate, as shown in the NHANES results. The lesson that I would draw, instead, is that tracking

information can be convincing to key stakeholders and to policy makers. It might be informative to have further discussions with Cal-EPA about other examples of policy opportunities that could arise from tracking.

4. Linking

There seems to be a lot of confusion about what linking of data will contribute to environmental public health tracking. The differences between linking and research are not well defined. It would seem that the discussion in the expert working group report (at page 39) could be clearer. The draft cites two research studies as examples of linking. Obviously, these studies are valuable in trying to better understand etiological relationships. Is the working group suggesting that similar approaches would be done on a statewide basis as part of an on-going surveillance or tracking system? The following paragraph describes some of the issues with data linking. It might also be appropriate to point out that data linkage can very easily fail to detect relationships that do in fact exist if it is not done in such a way as to take into account other factors that affect disease outcomes or if the incorrect metrics are used. This may be the more significant issue.

5. Components of Monitoring for Environmental Contaminants

The draft, starting at page 85, organizes its discussion of data about environmental contaminants both by media (air pollutants, water pollutants) and by chemical type (metals, persistent organic pollutants). This is somewhat confusing, as metals are also air pollutant and water pollutants, and not all environmental media are treated very fully (particularly food). Could this be organized more consistently?

6. Community and Stakeholder Contributions and Needs

This section is very interesting and innovative and is a good contribution to the field of environmental public health tracking.

D. Chapter Eight: Findings and Recommendations

Finding #1: Data clearinghouse (page 134)

The discussion of the costs of chronic disease seems somewhat misplaced here, as this discussion pertains to many of the recommendations.

It might be worth considering the idea of housing the Office of Environmental Health Tracking in Cal-EPA for the simple reason that most of the authorities to address the environmental factors that may be found to contribute to chronic disease reside in Cal-EPA.

The limited staffing proposal seems inadequate for the scale of the enterprise.

Finding #2 (p. 137)

The first bulleted recommendation should support “timely,” rather than “more timely” reporting of data. The sense of this recommendation is that this refers to reporting in a way that will allow public access, but it may be helpful to clarify this.

Finding #3 (p. 138)

It would seem that something might be said about the need to fund the essential infrastructure. It takes more than leadership.

The first recommendation should describe what is needed to fully fund the cancer registry, rather than using vague statements like “strong commitment to sufficiently maintaining this important resource.” This responsibility falls upon both the executive and legislative branches.

In the second bullet, the budget needs should be more clearly identified. Describing “lost positions” is very vague and hard to relate to any public health outcome.

Finding #4 (p. 139)

The recommendations in this section seem quite inadequate to address the issue described. They need to be broadened to fully address the issues noted. Please also see the comments on the section in the executive summary. The recommendations for biomonitoring and exposure assessment in the following sections are much better developed. Perhaps this portion of the analysis would benefit from input from agencies with more experience and expertise in this area.

Finding #5

As noted elsewhere, it may be worthwhile to explore what would be involved in obtaining data representative of California from NHANES, as an alternative to setting up a new survey and testing program solely for California. The recommendations on biomonitoring could be developed more specifically.

Finding #6 (p. 143)

The document should explain why the disease proposed for new registries are selected. Why these and not others identified as a priority?

Finding #7 (p. 145) - Clusters

The finding about clusters seems to be rather confused. One issue is to define whether an observation of a number of disease cases is a cluster (or not). This needs to be addressed independent of what you think the etiology might be. This does not seem to be addressed in this draft, here or elsewhere. The finding has a broader title than the text, and it would seem that this might be divided into two parts, because the cluster related issues may or may not be the ones that communities are most interested in. (the description of community projects and concerns in the document would suggest not).

Finding #8 (p. 146)

In the title, “tenant” should be changed to “tenet.”

Disparities in exposures and distributions of pollutants should be investigated, in addition to those in outcomes. Methods need to be developed for this.

E. Page Specific Comments and Wording Suggestions

It might strengthen the report to add a page or two that summarizes the breadth of presentations that were heard and considered by the Expert Work Group. The report now says that the meetings were open to the public, but significant efforts were made to bring in speakers to address a variety of issues, and this might be appropriate to acknowledge as well.

1. Executive Summary

Because (however unfortunately for them) many readers will review only the executive summary, it is obviously important that it be as informative, readable, and representative of the larger document as possible. Here are some specific wording comments.

Responsibility of the expert working group. In the fourth line, it is odd to say that the working group is “recommending” costs. Maybe add an additional verb here and say that the group is “recommending” approaches and “identifying” costs.

Do you need a hyphen between environmentally and mediated?

It is important that the executive summary NOT assume any knowledge of technical terminology or jargon. In that vein, the word “prevalence” should be re-stated in commonly understood language (maybe instead of prevalence, say the percentage of people with asthma). In the third paragraph, the phrase “asthma exacerbations” is a rather ugly formulation – maybe say something like “about one third of the asthma attacks in children.”

In the last sentence of the second full paragraph, something needs to be added to link the idea that establishing tracking will do something about reducing disease. Maybe rephrase to say something like: “One key to reducing the toll of environmentally related chronic disease is the establishment of a cost-effective environmental health surveillance system. Such a system is needed to give the State the information it needs to improve pollution and health prevention programs and reduce these kinds of diseases.

You say that you are including biomechanical stressors as a form of hazard, but this term is not defined and I don’t think you actually do. Maybe leave it out at least of the executive summary as something that people really don’t need to puzzle over. (What are they anyway?)

The last paragraph on the first page has too many different ideas and should be divided at least into two paragraphs and maybe three. In an executive summary you want one idea per paragraph so people can easily skim.

In the goals, I really do not like the terminology of “hot spots,” as some of the things that we expect to be increased may increase by age or ethnicity not solely by locale. Putting it this way suggests both that the key determinant is geographical and also that the areas are small enough to be considered to be “spots.” This is not going to prove to be the case.

In the third goal, about linking hazard information and disease information to generate hypotheses about possible connections, it seems like this might be able to be stated in a way that would sound more compelling to the public, many of whom will have only a dim idea of what a hypothesis is and why having one makes any difference whatsoever. Maybe something like: “Link environmental hazard information and disease information to help to understand possible connections and identify areas where follow-up action or research is needed.”

Under organization of the report, the second sentence is not grammatical (lack of parallel structure).

The recommendations for a “clearinghouse” in the executive summary does not seem to be quite the same as what the body of the report says about an office. It might be good to review one against the other and reconcile.

2. Other specific comments

On the list of acronyms, I wonder whether you could get by with using fewer. Some of these are fairly well known, but every single acronym you use is a barrier to understanding for somebody.

At page 18, I would not be so bold as to say what the legislature may intend to do, as is now written in the second paragraph.

At page, 20 in the first full paragraph, maybe change “inactivity” to “degree of physical activity.”

At page 24, I would suggest in the second sentence simply summarizing the relative proportions of the top four or five groups, rather than pointing out the proportion of two. The way it is now may read as if the assumption is being made the “white” is the norm.

At page 24, what is used to define “poverty” should be explained. There are lots of ways to do this, and results can vary considerably depending on which you pick

At 25, what about mortality from air pollution? This is a very important effect. Also, what about birth defects?

At page 27, it might be appropriate to point out that there can be an interaction between genetic and environmental factors in that genetic factors can increase (or decrease) susceptibility to environmental factors.

At page 29, in the last paragraph, some explanation of what a registry is should be offered. (More people are going to think of weddings than of cancer.) It might be useful to add a paragraph or two that summarizes the main types of disease tracking for those who may not be conversant with this.

For cancer, childhood cancers deserve specific consideration. Some of them appear to have environmental links. These could be important sentinel events and children are not as subject to the influence of other factors (like age) that contribute to cancer risk in adults. It is important to consider individual types of cancer and not just cancers as a whole.

At page 32, are the numbers in figure 2.3 correct?

At page 33, in the first line, we know that just about everybody in the US is at increased risk for cancer and other health outcomes due to hazardous air pollutants.

At page 38 (and elsewhere), it would be helpful to clarify what types of costs and benefits are being discussed. Generally, what types of benefits were considered? The great benefits attributed to reductions in mortality might suggest that this outcome should be considered relevant for tracking.

In the last paragraph, it is unclear what is being counted as the burden of disease. Some medical costs accrue to the State but not all do. Maybe when you say the “state”

here you really mean residents of the state? (There are better references for willingness to pay.)

Page 41, point 1 – the title used does not reflect the breadth of the text. I would avoid using the phrase hot spots, as noted above.

At page 43, in the section on Healthy Cities and Planning, it might be appropriate to mention the significance of the “walkability” of cities and suburbs and the importance of access to areas where people can exercise. This is related to planning but is increasingly being seen as a key determinant of health as well. Many other planning issues are also relevant – you may wish to review the guidance document on the significance of land use decisions for air quality and how local planning authorities can make better decisions now being prepared by the Air Resources Board. There are many issues and remedies besides buffering traffic.

At page 46, in the table, using “endocrine disruptors” as a pollutant category seems somewhat odd. Isn’t endocrine disruption an outcome? As noted elsewhere, there are other air pollution related outcomes including mortality that should be included. It is also important to separate out cancers. It would be advisable to add children’s outcomes as a target for tracking.

At page 53, another reason to track children’s outcomes separately and to make this a priority is that children are not subject to the effects of aging. There may be fewer factors that co-contribute to disease in children.

At page 55, it would be helpful to provide a little more explanation before launching into the list of data elements for a health tracking database. It would be helpful to discuss the major types of approaches to health outcome tracking. In the list of data elements, it may be helpful to explain that the unique identifier is to identify the individual. It seems that this would be an appropriate place for some discussion of privacy concerns. Suggesting that social security numbers be used in a tracking system will generate concern. How can this be done in a way that ensures individual privacy and reduces the potential for identify theft?

At page 58, the issue of response rates for surveys is raised. This warrants further discussion, as response rates are diminishing, and the relatively low response rate is a concern about CHIS.

At page 61, it might be appropriate to find out whether California intends to implement the child asthma module for BRFSS. If so, this could provide some additional information. Also, I understand that the youth risk factor survey is obtaining information about asthma in some states. This may be worth investigating.

At page 62, it says that deaths from asthma do not give an accurate picture of the burden of disease. This is certainly true. They also do not give much of a picture of any environmental component, as deaths represent extreme failure of medical care. Perhaps this could be explained more clearly.

At page 69, there is a need to consider how a tracking system might be able to look at the more subtle neurodevelopmental effects that have been found to be associated with exposure to methyl mercury or PCBs. These will not be detectable clinically, yet assessing such more subtle effects may be critical to understanding the effects. To

provide the parallel to the ever-popular lead example, we did not fully understand the magnitude of effects of lead exposure until they were associated with subtle reductions in IQ. These were not detectable clinically, yet represent a highly significant loss of capacity for the population as a whole.

At page 83, the discussion of hazard tracking is unclear. The text says: “. . . hazard tracking involves information on indicators that correlate with potential for exposure.” What does that mean? Use of the term “hazard” is confusing, as noted elsewhere, because part of what has to be done in a tracking system is to determine what constitutes a hazard.

At page 84, the list of data elements seems somewhat confusing because it includes elements that would be appropriate for data systems that include measurements of the use or release of environmental agents from fixed locations as well as data elements that would be appropriate for the very different types of data systems that include measurements of environmental agents in environmental or exposure media. It might be clearer to distinguish between these two. The sentence, “Number of days that the ozone standard was exceeded is an example of a database that fails to meet our criteria because it does not report the ambient concentration of ozone in air over time as a continuous variable” is very confusing in that it mixes up a measure (number of days) with a database. Some air pollutants are measured on a continuous basis, but some are not.

At page 85, the list of data elements seems to combine those that would be relevant for a database with measurements of concentrations of environmental agents in individuals as well as data elements for databases for measurements of environmental agents in environmental and exposure media (which are also covered in the previous section). This is very confusing.

At page 86, the discussion seems to confuse data elements with criteria. I don't see actual criteria for a data base, though the text seems to use the preferred data element as criteria.

At page 87, the discussion about types of databases does not include one important type of data: measurements or estimate of concentrations of environmental agents in environmental or exposure media. Such concentrations can be estimated using models.

At page 88, the discussion about the limitations of the availability of data about the toxicity or potential for health effects for many chemicals used or produced in the US is a key reason why it is impossible to reliably ascertain at this time which chemicals may represent “hazards.”

At page 90, the list of compounds for tracking seems very incomplete.

At page 91, the National Air Toxics Assessment provides estimate of the ambient concentrations of about 30 of the hazardous air pollutants. This should be added to the list of key data sources. This section should also include the Toxics Release Inventory, which is referred to later.

The CDC is conducting biomonitoring. In the absence of state data, these results are worth considering.

At page 92, in the discussion of the CHAPIS system, the issue with the inventory is not that it “undermines the basis for the models.” The models may be sound, but if the inventories are wrong, then the models will not have accurate inputs and the results may not be correct. It seems unlikely that CHAPIS, as currently designed, will have sufficient resolution for health surveillance.

At page 95, the focus in terms of health effects seems to be focused much too narrowly on cholinesterase inhibition. Many other longer term effects, including neurological effects and cancer, are relevant. The recommendations need to be broadened to consider how to better relate pesticide exposure and such disease outcomes.

At page 98, the text confuses drinking water surveillance (for water in drinking water systems) and water quality surveillance (for water in lakes, streams, etc.) It may not be true that having water utilities provide their billing addresses will allow tracking of drinking water quality for individuals, as single utilities may have complex water systems with multiple sources and varying patterns of contaminants. It would seem that a more integrated system for sampling for emerging contaminants is needed.

At page 101, the report jumps from a (mostly) media-based approach to categorizing contaminants to one based on the chemical properties of the contaminants. Why do this? It seems like the presentation should be organized consistently, one way or the other. Metals are a concern for every environmental medium. This discussion seems to be mostly about contaminants in food; it might make more sense to add a section that focuses on contaminants in food (which would also need to bring in some of the discussion about pesticides).

At page 111, the draft recommends the use of the PACE process. Has this been evaluated?