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Measuring Chemicals in People – What Would You Say?  
A Boston Consensus Conference on Biomonitoring

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**CONSENSUS STATEMENT**  
**DECEMBER 11, 2006**

“GOVERNMENT BY THE PEOPLE AND FOR THE PEOPLE.’  
WE REPRESENT THE GENERAL POPULATION AS WE COME  
TOGETHER FOR A PURPOSE, TO MAKE SOMETHING HAPPEN.”

*- Lay panel member*

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## PREAMBLE

We, the members of the lay panel of the Boston Consensus Conference on Biomonitoring, have spent the last two months considering the exposure of people to chemicals and the related risks associated with them. This topic “hits close to home” for many of us, through personal experience or the experience of those we love – our families, our children, our grandchildren. Some of us worry about exposure through our workplaces, others have expressed fears about the environment in which we live and the foods we eat, still others are concerned about the effects of medicines.

Biomonitoring is the science of measuring foreign chemicals in our bodies. It has been an important tool in reducing and preventing exposure to harmful chemicals, like lead or second hand smoke, and is being used in many new ways to understand the extent and nature of the chemicals that have found their way into our bodies and, in some cases, are building up there, like flame retardants or mercury. For this reason, and others presented later in this statement, we feel that biomonitoring should receive serious consideration for public funding and support.

The scientific community is still struggling with the difficult problem of relating much of the data acquired by biomonitoring to health consequences, if any. We are learning “how much” we may have in our bodies, but not always “how come” or “how to respond” to what we find out.

We recognize the many difficult questions biomonitoring presents. Therefore, we have identified and agreed on the following five priority areas of concern as warranting further exploration and consideration as the use of human biomonitoring expands. They include:

- Establishing responsible surveillance programs;
- Using biomonitoring data to influence corporate and government behavior;
- Educating the general public about biomonitoring;
- Addressing the issues of ethics, confidentiality and disclosure; and
- Final thoughts on public policy.

We offer our hopes, concerns and recommendations in the following consensus statement.

## ESTABLISHING RESPONSIBLE SURVEILLANCE PROGRAMS

Chemicals are showing up in human bodies and, through the use of biomonitoring, their presence can be measured more accurately and easily than ever before. By providing the ongoing, systematic collection, analysis, interpretation, and dissemination of biomonitoring data, surveillance programs demonstrate to both the scientific community and the public that this is the case, and potentially offer real information for public health intervention.

We believe that responsible biomonitoring surveillance programs will positively impact public health and further science by providing data on the presence of environmental chemicals in the human body. It is our hope that as a result of detecting chemicals of interest, funds will be allocated for epidemiological studies that follow a group of people over time, including children at birth, people at various stages of life, and populations at risk, and attempt to link exposure to chemicals to health outcomes. Additionally, biomonitoring surveillance will allow us to assess the performance of public health interventions. It may also determine and track patterns of exposure in different communities.

Our specific concerns include:

- The possibility that we are not testing for all chemicals of interest;
- Whether those communities who most need this tool will have priority access to it;
- Whether expectations will be set reasonably and communicated properly, results used responsibly (i.e., no discrimination or misuse of the information), and concerns about the information itself, including assurance that individuals will have access to their results and that privacy will be maintained (see section on ethics, confidentiality and disclosure);
- Whether there is appropriate follow-up for individuals who participate in a surveillance program; and
- Understanding who should be allowed to do the testing and who is allowed to use the results.

We agree that the oversight boards for biomonitoring surveillance programs should be comprised of different stakeholder groups. The boards should include individuals from affected communities, scientific experts, and not be dominated by industry. For instance, the lead surveillance program in Massachusetts includes different interests on its advisory council, including parents of children who live in low income communities and may be more affected by lead, the

real estate community, and others. It is our hope that trust will be built in communities when they see themselves represented, along with other stakeholders, in the oversight process.

In addition to the federal surveillance program, general state-wide biomonitoring programs are useful because:

- The CDC program gives a national snapshot, but does not indicate what is happening in states or regions. Collecting state-wide data seems to be the next step in data collection.
- Winds and climate conditions cause chemicals in the environment to be deposited in different patterns, so some areas of the country are more impacted than others. State-based data will indicate if there are concerns specific to a particular state or region.
- Results may empower individuals who participate to make their own choices about products to use and behaviors.
- Many important public health decisions are made at the state level. States are often the driving force behind regulations. Knowing more about chemical exposures in a state will allow better public health decisions to be made.

As state programs are established, it could be useful to create opportunities for states to learn from each other by sharing the trial and error of implementation of state programs.

However, serious concerns about such programs have also been expressed. There is a risk that communities or local areas with higher levels of detected chemicals may be stigmatized, possibly adversely impacting them economically and socially. The objectives of any state-wide program need to be made clear – for example, is it designed to provide surveillance data or is it designed to address a specific problem where there is a known causal relationship between a chemical and disease (e.g. lead).

There is certainly a need for specific state-wide surveillance programs for particular chemicals, such as lead, where the health outcomes are more clearly established. In these cases, we have identified a concern and can offer a solution. As the toxicity of chemicals is established, they could be introduced into some kind of biomonitoring framework.

## USING BIOMONITORING DATA TO INFLUENCE CORPORATE AND GOVERNMENT BEHAVIOR

We believe biomonitoring data can influence corporate and government behavior by highlighting the public and environmental health concerns related to exposure to chemicals. For example, we are hopeful that companies and government researchers will find that biomonitoring data stimulate innovations in “green chemistry,” the development of alternatives to potentially toxic and persistent chemicals.

In addition, we believe that biomonitoring could be a stimulus and encouragement to start new “green companies.” Education and consumer awareness, focused by biomonitoring data, could shift interest and attention to these companies, giving them a marketing feature in their competition with companies that use more toxic chemicals in their manufacturing. The growth of these green companies, in turn, would create new markets and jobs, lead to reduced production costs for insurance, storage, and transportation, and promote a healthier environment.

We also hope biomonitoring data can influence corporate and government responsibility in those instances where communities have been disproportionately affected by involuntary chemical exposures through their environment. Because these are often low income communities and communities of color, this is an environmental justice issue the panel felt was an important potential consequence of a biomonitoring program.

We have a number of specific concerns with respect to biomonitoring and corporate and government responsibility. These concerns are as follows:

- Many products contain chemicals not disclosed to consumers;
- Biomonitoring data that show an increasing trend in exposure to a chemical, even when the health effects are uncertain, should be treated in a precautionary manner that seeks to reduce or eliminate exposure; and
- We recognize that the allocation of public funding – how funds are spent, and what chemicals are looked at – is subject to a variety of interests and attempts to influence it outside of the science. We recognize that there is a historical reality that weak penalties for polluters will not prevent chemical pollution. Our hope is that biomonitoring, by helping us understand which chemicals are increasing in our populations and guiding research on health outcomes, will lead to greater accountability and responsibility on the part of industry relative to the chemicals they use, to more consistent compliance with regulations, and to advances in public health and medicine.

There are many issues relative to corporate and occupational biomonitoring of employees. Time did not allow us to address this aspect of the topic in depth.

Educating the general public about environmental health and biomonitoring is an essential element in encouraging and enabling informed participation of the general public in biomonitoring programs. Biomonitoring data also can help the media explain and illustrate the problem of the increase in toxic chemicals in our environment.

Participation in a biomonitoring program for many people could create an introduction and connection to the health care system itself. The experience of people in a biomonitoring program can be both an opportunity and a risk for their attitude and trust in a health services system that has not always served all members of our community equally. It is also an opportunity to foster a positive attitude toward preventive health care, not just occasional use of the system for crisis situations. If biomonitoring were an appropriate diagnostic tool, we would want to ensure that the lack of health care coverage would not be a barrier to participation.

Public awareness can be promoted in ways similar to the state's annual Lead Week, enlarging it to other environmental issues that can promote good health. If the biomonitoring program is incorporated into community-based participatory research, it can also forge new relationships between scientists and the community that are beneficial to both parties.

Sharing information from credible sources with the public on a regular basis will ensure that all layers of society and people of all ages have access to information obtained from biomonitoring studies, enabling people to make more conscious choices about their health and the products they use and consume. This information sharing must be accessible and community-based, with a goal of:

- Alerting people to invisible or hidden dangers in our chemical environment, threats that may be serious but not visible; and
- Helping people become less susceptible to manipulation and other misuses of biomonitoring results.

However, we have some specific concerns with respect to education on biomonitoring, which include the following:

- The information taught or communicated has to be precise, which includes conveying accurate information about what is known and not known about cause and effect of exposure to monitored chemicals. This can be difficult to do and take time; however, it is an essential part of educating the general public in a way that does not raise inappropriate alarm. Similarly, recognizing that the same information is often communicated differently by different stakeholders for self-interested effect, every effort must be made to present an unbiased and objective review of the facts.
- With a goal of reaching populations most in need of this information, we would want to make sure there is broad outreach, education, and communication, being attentive to geography, socio-economic class, and ethnicity, and sensitive to issues of accessibility (e.g., language and TV/computer access). Part of this concern includes the importance of preparing people and communities to receive the information, making sure that an infrastructure is in place to support people's reactions to what they learn, and providing follow-up services.
- Education and communication are a valuable part of any biomonitoring program, and therefore must receive the necessary funding and resources.

In summary, interest in biomonitoring could lead to interest in basic health care and other health-related concerns, as well as increased participation in the larger health care system. However, we want to be certain that people are not only informed and educated, but that there is an infrastructure that allows them a voice and the opportunity to participate in decisions about their health.



We believe that addressing the issues of ethics, confidentiality, and disclosure will have a significant impact on the success of biomonitoring programs.

- It is essential that discrimination based on test results, and other misuses of biomonitoring information be prevented;
- It is important that any planned disclosure of results be clarified up front and that appropriate confidentiality be assured; and
- Biomonitoring may not be accepted by the public unless they trust that the process is confidential; for instance, people who do not trust the health care system generally may not trust biomonitoring specifically.

Our specific concerns with respect to the ethics, confidentiality and disclosure aspects of biomonitoring programs include:

Confidentiality, privacy and the safeguarding of personal data generated by biomonitoring is a great concern. Personal data and health information are often shared amongst insurers, employers and potential lenders without the knowledge or consent of an individual. This can lead to individuals being stigmatized. In addition, data which may not have much relevance today may gain greater significance in the future.

There needs to be a wider discussion about protecting the privacy of this type of information and to what extent confidentiality can be maintained by the researchers and those who seek to apply this data to develop public policy.

It is the consensus of the panel that information derived from biomonitoring, as with genetic testing, for example, should be statutorily exempted from being transmitted or shared with employers, insurers or others as part of the

medical history, without the express written consent of the individual. Specifically, it is recommended that legislation be enacted to ensure this.

The panel recommends a reporting protocol that fully educates the participant about the potential implications of opting in or opting out of receiving their test results. As examples, if an individual opts out, it is possible that they may be opting to NOT be told their test results, even if the results have potential adverse health consequences. On the other hand, if they opt in and receive their results, individuals need to have an awareness of situations where they might be urged to disclose the information, such as to a doctor, and to understand the implications of such a disclosure.

As part of the reporting protocol, we also recommend inclusion of any specific action steps for those who have high levels of exposure and education about ways to reduce future exposure.

We believe that safety and security in biomonitoring programs will positively impact the future of biomonitoring by gaining the public trust, which leads to:

- People being more inclined to participate in biomonitoring programs, which leads to...
- More robust data, which leads to...
- People wanting knowledge about biomonitoring, which leads to...
- Greater public demand for this information, which leads to...
- More funding for research, which leads to...
- More treatment for the adverse health outcomes related to toxic chemicals in our environment over the long-term.

## FINAL THOUGHTS ON PUBLIC POLICY

We acknowledge the time, energy, and funding required to shape public policy, legislation and regulation. Nevertheless, we believe that public policy should play a key role in guiding biomonitoring efforts and the use of the data they generate. Specifically, it should offer the guidelines within which biomonitoring surveillance programs are conducted. Then, once

the data from those programs are available, public policy should provide the framework for translating the results into meaningful actions. While we have not explicitly devoted a section of this statement to public policy, we respectfully ask that the recommendations and concerns expressed in this statement inform its creation.

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