Questions for Experts
December 9, 2006
Boston Consensus Conference on Biomonitoring

Rachel Morello-Frosch, PhD, MPH
Carney Assistant Professor, Brown University Department of Community Health, School of Medicine & Center for Environmental Studies
Julia G. Brody, PhD
Executive Director, Silent Spring Institute

Re. ETHICS, CONFIDENTIALITY AND DISCLOSURE

- Based on your research interviewing scientists, what are some different perspectives on reporting results back to individuals who have participated in biomonitoring studies (e.g., report all data, report "unsafe" levels, not report)? What are the different strategies that have been used for reporting (e.g., phone call, letter, via physician)?

- From your research and your own experience on biomonitoring studies, what information do participants have a right-to-know (e.g., their exact levels, levels compared with others, known or unknown health effects associated with levels)?

Re. RESPONSIBLE SURVEILLANCE PROGRAMS

- Members of the lay panel have discussed the importance of trust in the success of a voluntary biomonitoring surveillance program. What role if any will mistrust of government and large institutions play in biomonitoring programs as it relates to disenfranchised people and communities of color?

- What are the different perspectives on whether or not biomonitoring surveillance programs should study “hot spots” (i.e. geographic areas of higher exposures or more vulnerable populations)? Please also address concerns about stigma and economic discrimination of communities based on biomonitoring results.

Patricia Roche, JD
Associate Professor, Department of Health Law, Bioethics and Human Rights, Boston University School of Public Health

Questions to address in 20 minute presentation:

Re. ETHICS, CONFIDENTIALITY AND DISCLOSURE

- How could someone be hurt (e.g., financially, legally, emotionally) by participating in a biomonitoring surveillance program? What are the mechanisms that are meant to prevent this from happening, and are they effective? Here are some ways in which these issues arose:
    - Concern about discrimination by employers: Could a company require biomonitoring of its employees? Do employers have the right to ask a potential employee for access to their biomonitoring results, if they know they exist? Could biomonitoring test results become the basis for employment discrimination? Could employee testing lead to dismissal or to the employer's disclosure of results to insurance companies?
    - Concern about discrimination by insurance companies: Could someone who participated in a biomonitoring surveillance program experience discrimination based on test results (i.e. not be insured or face higher premiums)? Also, insurance companies sell data – could biomonitoring data be sold?
    - Concern about confidentiality: What safeguards would maintain confidentiality of participant data? What are ways to ensure that personal data won't be shared 5 years down the road or at all? Is biomonitoring information able to be subpoenaed in court cases? Is it possible that an individual could inadvertently share their biomonitoring results with someone (including a medical doctor) and this could hurt them in the future? Could biomonitoring results be part of doctor-patient confidentiality?
    - Other related issues: Do individuals who have been biomonitored need individual legal protection? Could a surveillance program that tested individuals for a chemical with unknown health effects be obligated to tell them years later that their levels are now understood to be unsafe?

Re. PUBLIC POLICY, LEGISLATION, AND REGULATIONS

- Members of the lay panel are very interested in how data from biomonitoring could be used to inform public policy. What are ways that biomonitoring results may be used to influence policy, legislation, or regulations? How could results be used to create accountability for chemical pollution (e.g., assigning responsibility for clean-up where there is exposure)?

Questions to be prepared to address in the Q&A (these may be asked, in addition to other questions):

- The belief was expressed that the Americans with Disabilities Act has not been effective at protecting those it is meant to protect, and left the burden of proof on individuals. Is it possible that people who have elevated chemical levels with unknown health effects be a legally protected class under the American Disabilities Act or something similar? How can we ensure that it will be effective?

Roy Petre
Senior Policy Analyst, Center for Environmental Health, MA Department of Public Health

Re. RESPONSIBLE SURVEILLANCE PROGRAMS

- Could you provide a brief history of the lead surveillance program in MA? (e.g., what were some of the reasons it began and where did the pressure and resistance come from?)
- Is the lead surveillance program mandatory? If so, what does this mean? Are individuals penalized if they do not have their children biomonitored (tested for lead levels)?
- How effective is the program at reaching all children, including those without regular health care?
- Does the program highlight "hotspots" or areas in particular need of attention and resources to mitigate lead exposure?
- Is data from the MA lead surveillance program used to make state-to-state comparisons? Have states learned from each other by sharing the trial and error of implementation of surveillance programs?

Re. ETHICS, CONFIDENTIALITY AND DISCLOSURE

- What happens to the surveillance information?
  - Do individuals have access to their results?
  - Do results go on medical records?
  - Are results confidential?
  - How are results stored and with what security?

Re. EDUCATION AND COMMUNICATION ON BIOMONITORING

- How are results reported to families and to the general public?
- Does the program include efforts to create trust and do outreach in communities by health care facilities and/or public health agencies? Are they effective?
- How has the blood lead level that is considered to be safe changed over time, and are parents notified if their child had a blood lead level considered safe at the time but not under current standards?

Re. PUBLIC POLICY, LEGISLATION, AND REGULATIONS

- Does the state participate in any other types of biomonitoring for chemical exposure? What capacity does the state have to do so?
- How do results of the biomonitoring program get translated into actions and policy (e.g., in outreach and education as well as determining what level of exposure is considered safe)?

Carol Henry, PhD, DABT
Vice President, Industry Performance Programs, American Chemistry Council

Questions to address in 20 minute presentation:

- Some people are upset when they learn about the presence of industrial chemicals in their bodies. What role does this play in shaping industry's position on biomonitoring?

- When health risk of a chemical exposure is uncertain or not known but biomonitoring data indicate an increasing trend, should this translate into action or policy? If so, what might this be?

Re. RESPONSIBLE SURVEILLANCE PROGRAMS

- Members of the lay panel have expressed concern about the influence of special interests in controlling biomonitoring efforts (i.e., what chemicals are tested, who is tested, where testing is done). Who should participate in the oversight of biomonitoring surveillance programs, and what credentials or experience should they have?

Re. CORPORATE/GOVERNMENT RESPONSIBILITY AND ACCOUNTABILITY

- What role should biomonitoring results play in creating accountability for chemical pollution (e.g., assigning responsibility for clean-up where there is exposure)?

Questions to be prepared to address in the Q&A (these may be asked, in addition to other questions):

- Why did the ACC and industry groups oppose the earlier versions of the California bill?

- Could you explain why the ACC did not want the California legislation to include the biomonitoring geographic areas or "hot spots" where there may be higher exposures?

Ted Schettler, MD, MPH
Science Director, Science and Environmental Health Network

Questions to address in 20 minute presentation:

- How do you respond to the suggestion that efforts by NGOs (e.g. the Environmental Working Group) to biomonitor people and publicize results are unscientific, done for political purposes, and unnecessarily alarming to the public?

- When health risk of a chemical exposure is uncertain or not known but biomonitoring data indicate an increasing trend, should this translate into action or policy? If so, what might this be?

Re. RESPONSIBLE SURVEILLANCE PROGRAMS

- Members of the lay panel have expressed concern about the influence of special interests in controlling biomonitoring efforts (i.e., what chemicals are tested, who is tested, where testing is done). Who should participate in the oversight of biomonitoring surveillance programs, and what credentials or experience should they have?

Re. CORPORATE/GOVERNMENT RESPONSIBILITY AND ACCOUNTABILITY

- What role should biomonitoring results play in creating accountability for chemical pollution (e.g., assigning responsibility for clean-up where there is exposure)?

Questions to be prepared to address in the Q&A (these may be asked, in addition to other questions):

- Regarding your personal experience reporting the results of a biomonitoring study: Did participants receive their results voluntarily? Were their physicians involved, or did you give them guidance on whether to share this information with their physician? Did you assure confidentiality? If so, how did you maintain confidentiality? How did you communicate results for those with high levels of exposure? Were there any specific action steps you were able to recommend?