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

September 24, 2007

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Department of Environmental Health

Public Health Applications of Human Biomonitoring
US EPA
Consensus Conferences

- Danish Board of Technology → Parliament
  - Argentina, Australia, Belgium, Canada, Israel, Japan, New Zealand, South Korea

- Participatory Technology Assessment (pTA)
  - European Citizens’ Deliberation method
    (Nine European countries)
Boston Consensus Conference

Objectives:

• Educate the general public and stakeholders about biomonitoring, and related ethical, legal, social and scientific issues.

• Gather input on the topic of biomonitoring from informed laypeople and learn from their unique perspectives.

Funding:
National Institutes of Environmental Health (NIEHS)
  – Communications and Ethics
  – Outreach and Translation,
    Superfund Basic Research Program
Why Biomonitoring?

- Scientific complexity
- Issues of controversy
- Pending legislation
Steering Committee

Lois Adams, EPA Region 1

George Annas, JD, MPH, Boston University School of Public Health

Tom Burke, PhD, MPH, Johns Hopkins Bloomberg School of Public Health

David Carpenter, MD, University at Albany School of Public Health

Howard Frumkin, MD, DrPH, National Center for Environmental Health, Agency for Toxic Substances and Disease Registry

Carol Henry, PhD, DABT, American Chemistry Council

Ted Schettler, MD, MPH, Science and Environmental Health Network
## Assembling the lay panel

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Chemicals in People – What would you say about it?

Should people be tested for chemicals in their bodies?
What if we can’t say what results mean for health?
How much should people know?

Participate in a forum that gives Boston residents a voice on these questions. Come to 3 weekend meetings to learn about and discuss them.

You will be paid for your time. No experience needed.

For more information: info@biomonitoring06.org or 617-414-1075

Sponsored by the Boston University School of Public Health

www.biomonitoring06.org

> 100 responses

85 Questionnaires returned

~ 20 Interviews

Final 15: Teacher, great great grandmother, truck driver, detention center staff, singer, actor …
First weekend

- Working definition of “consensus”
- Building trust

Expert Presentations
- Intro to toxicology, epidemiology, and public health
- Intro to biomonitoring
Second weekend

Expert Presentations

• Larry Needham, CDC: NHANES biomonitoring surveillance program
• Amy Kyle, UC Berkeley: CA legislation
Lay Panel Questions

• Are there examples of corporations that have been held accountable or that have changed their behavior based on the results of biomonitoring?

• How could someone who participated in a biomonitoring surveillance program experience discrimination based on test results?

• How might biomonitoring results get translated into action and policy?

• What did California do around biomonitoring education and awareness?

• What are some perspectives on who should sit on the oversight boards of biomonitoring surveillance programs?
Third (final) weekend

Saturday- Expert presentations

Sunday- Deliberation and writing

Monday- Presentation of consensus statement
Expert Panel (morning)

Rachel Morello-Frosch, PhD, MPH, Brown University School of Medicine Department of Community Health, and the Center for Environmental Studies

Julia Brody, PhD, Executive Director, Silent Spring Institute

Ethics, confidentiality and disclosure; and responsible surveillance programs

Patricia Roche, JD, Boston University School of Public Health, Department of Health, Law, Ethics and Human Rights

Ethics, confidentiality and disclosure
Expert Panel (afternoon)

Roy Petre, Senior Policy Analyst, Center for Environmental Health, Massachusetts Department of Public Health
Ethics, confidentiality and disclosure; responsible surveillance programs; education and communication on biomonitoring; and public policy, legislation, and regulations

Carol Henry, PhD, DABT, Vice President, Industry Performance Programs, American Chemistry Council
Responsible surveillance programs; and corporate/government responsibility and accountability

Ted Schettler, MD, MPH, Science Director, Science and Environmental Health Network
Responsible surveillance programs; and corporate/government responsibility and accountability
Consensus Conference: Presentation of findings
Consensus Statement

- 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
- Thoughts on public policy
Establishing Responsible Surveillance Programs

- State-based programs useful in addition to federal program

- Oversight boards should be composed of different stakeholder groups, including affected communities

- Concern that communities or individuals could be stigmatized by results
Using Biomonitoring Data to Influence Corporate and Government Behavior

• Biomonitoring data can be used to stimulate green chemistry and green companies

• Treat increasing trends in chemical exposure in a precautionary manner that seeks to reduce or eliminate exposure
Educating the General Public About Biomonitoring

- Key to achieving broad participation in biomonitoring programs

- Participation can be a point of entry into the health care system

- Information conveyed should include what is known and not known about cause and effect of exposure
Addressing Issues of Ethics, Confidentiality, and Disclosure

• Participants should be able to decide whether or not to receive personal results, “Right to know”

• With reporting, important to include action steps for reducing exposure where available

• Biomonitoring data should be statutorily exempted (like genetic testing) from being transmitted or shared with employers, insurers or others as part of the medical history
Conclusions

Value of diverse experiences

Lay people can understand complex information and make useful recommendations

A successful model for “mutual education”
"I think this panel has shown, to some degree of surprise to the scientific community, that the public can really understand the issues. This panel has moved biomonitoring forward."

Tom Burke, Johns Hopkins Bloomberg School of Public Health, Steering Committee member and NAS panel chair
"I'm very pleased with your comments on innovation in green chemistry because innovation for the industry is really the driving force for being successful...We will take your report and really try and incorporate and integrate it into future actions."

Carol Henry, American Chemistry Council, Steering Committee member
"This is a good way to include the voices of 'average folks' and their uniquely relevant experiences in the policymaking and public education process."

*Panel member*
Further Applications of “Consensus Conference” Model

21st Century Nanotechnology Research and Development Act (Dec. 3, 2003):
Requires… “public discussions, through mechanisms such as citizens’ panels, consensus conferences and educational events.”

National Science Foundation: Human enhancement technologies
Arizona, California, Colorado, New Hampshire, North Carolina, Wisconsin
Acknowledgements

• Members of the lay panel
• BU SPH Team: Jessica Nelson, Raphael Adamek, Traci Bethea, Tom Webster, David Ozonoff,
• Kagan Associates, LLC
• Steering Committee members
• Expert panel members
• Ned Crosby, Patrick Hamlett, Dick Sclove