“Biomonitoring Literacy” in the MIEEP/ Chemicals in Our Bodies Project: Developing Report-back Materials with Input from Study Participants

Biomonitoring California
Scientific Guidance Panel
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Motivation for Report-back

- California law requires results be made available to participants who want them.
- Experience with individual and aggregate report-back.
  - CYGNET Study focus groups
  - Cape Cod Household Exposure Study
  - Northern California Household Exposure Study
    - Richmond, CA
    - Bolinas, CA
- Advance "biomonitoring literacy."
  - Make complex information accessible to study participants and general public with varying literacy levels and knowledge of chemicals and health.

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Why Biomonitoring Literacy?

- Builds on national efforts to improve health literacy.
  - Degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions. (Healthy People 2010)
- Consistent with growing focus on public health literacy.
  - Incorporates social determinants of health and population health perspectives.
  - Will promote understanding and ability to act on societal-level factors that affect health, including chemical policies (Freedman et al., Am J Prev Med, 2009).

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Health Literacy Best Practices

- Find out what people want and need to know, what they understand, and how they want the information. Make it relevant to their cultures and situations.
- Aim for 6th-7th grade reading level. Half in U.S. have <high school education; most read 3 grades below actual grade completed.
- Group similar information, break up complex topics.
- Use shorter words & sentences, legible fonts, and easy to understand graphics.
- Limit number of concepts, and give examples.

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Usability Testing

Usability testing (UT) research identifies confusing or unappealing elements that hinder comprehension and use of informational materials, and evaluates possible solutions.

- Methods include structured interviews and questionnaires, observation, think aloud, task-oriented (partial list).
- Most common uses include developing written materials, web sites, and software.
- HRA conducts UTs to develop consumer health materials and websites (Neuhauser et al., AJPH, Dec. 09).
- Some evaluated uses include materials to choose health plans, instructions for medical devices, web sites for clinical trials.

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MIEEP/CIB Project Usability Testing

Goal: Assess report-back *prototype* with participants to inform development of results materials.

- Are main messages clear?
- Are materials understandable for people with varied linguistic and educational levels?
- Are there confusing or unappealing elements?
- Is interpretation of results meaningful?
- What information are we missing?

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MIEEP/CIB Project Usability Testing

Recruitment:

- CIB participants volunteered for usability testing

Demographics:

- 6 English (2 rounds) and 9 Spanish (4 rounds)
- Education: 6th grade to college degree (average high school)
- Average household income <$20,000
- Little prior knowledge about chemicals and health

Process:

- Semi-structured scripted interviews of 1-1 ½ hours
- Participant asked for general impressions, then asked specific questions about each document
- Changes made between rounds; final Spanish changes made in English versions

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How Prototype Was Developed

- Assessed 9 examples; adapted template from Silent Spring Institute/Brown University/UC Berkeley
  - Comprehensive, multiple formats, English & Spanish
  - Tested and evaluated in previous personal exposure studies
  - Used as example in CYGNET focus groups
- Health literacy principles guided development of initial CIB prototype:
  - Organized packet clearly: letter orients vs. informs, consistent labeling, easier to read graphics
  - Simpler vocabulary, consistent use of terms
  - Clumped information, reduced reading level

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Key Successes

- Participants appreciated sample results.

  "I got a lot of information here that I didn't know already. The study people already told me things, but there was a lot more here. The reason why people get cancer might be here. I grew up in the 70s and 80s and they didn't know much about all this. Maybe something back then contributed to my future bad health. The summary pages were very interesting."

- Nearly all correctly identified their own results in the charts, either exact number or estimate from chart scale.

- Most could identify whether they were lower or higher than other women in the study.

  "At first I'd think, "oh my God, there's a blue circle." Then I'd see that for some, none were found, then I'd see where I was compared to the other ladies and the national average, then I'd see how I feel."

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Key Successes

- Participants understood that “safe” levels for most chemicals are not established.
- Participants could easily figure out where they could get additional information.
- Understanding of Results Chart seemed to improve when they read the second chart.
- Most willing to read more materials (due to more chemicals) when mailed their actual results.
- Understood how they might have been exposed to chemicals and possible ways to reduce exposures.

Key Challenges

- Information volume.
- Understanding how personal results compare to:
  - National averages (CDC NHANES)
  - Levels of Health Concern
  - Results for other study participants
- Spanish speakers less likely to say they did not understand or to ask questions/suggest improvements.
- Spanish speakers had lower literacy, less knowledge of chemicals.

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Main Changes to Materials

- Sentences shortened; simpler and shorter words used throughout.
- White space added; information bulleted.
- Information put into Q&A format.
- Explanations of comparison values clarified and simplified.
- Navigation between/within documents clarified.
- Tables simplified and reformatted.

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What Biomonitoring Participants Want to Know

- What did you find?
- How much?
- Is that high?
- Is it safe?
- Where did it come from?
- What should I do?

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Final Report-back Template After Testing

Packet contains:

1. Cover letter
2. Summary of Results (text)
3. Results Chart
4. List of Chemicals Tested

Organized in chapters by chemical class

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Date

Name
Address
City, State, Zip

Dear _____:

Thank you very much for taking part in the Chemicals in Our Bodies Project in 2010. This project will help us learn more about chemical levels in pregnant women and their babies. We tested 85 mothers and their babies.

We tested the blood and urine of mothers for 2 kinds of chemicals: metals and pesticides. We tested the umbilical cord blood of babies for metals only.

When we collected samples from you and your baby in 2010, you asked to receive your results. Your results and your baby's results are attached in this packet. There are 2 parts:

Part 1: Metals in Blood	Includes a summary of results and a results chart for you and your baby
Part 2: Pesticides in Urine	Includes a summary of your results, a results chart, and a list of the pesticides tested

You can compare your results to:

- Results for other mothers and babies in this study.
- National averages, which are the most common levels for pregnant women in the U.S. Average levels are not necessarily safe.
- Levels of health concern. Levels above these may be a health risk. These levels are used to regulate some chemicals. Levels of health concern have not been set for most chemicals.

We hope to talk with you about your results. A staff member from the project will contact you to set up an interview. Meanwhile, **if you have any questions, please feel free to call the Project Coordinator, Jackie Schwartz, at 510-986-8925**.

Thank you very much for taking part in this project.

Sincerely,

Rachel Morello-Frosch, PhD
Tracey Woodruff, PhD
Rupali Das, MD, MPH
Project Co-Investigators

Pesticides

We tested for 9 pesticides. Pesticides are chemicals used to kill bugs, weeds, and other pests.

Have you found pesticides in my urine?

We found 6 pesticides in your urine. (We did not test babies for pesticides.)

Can I compare my levels to other levels?

You can use the *Results Chart* in this packet to compare your pesticide levels to:

- **Other women in the study.** We found pesticides in you and in most mothers tested.
- **National average.** This is the most common level for pregnant women in the U.S.
- **Level of health concern.** Levels above these may be a health risk. Levels of health concern have not been set for the pesticides we tested.

The next page explains more about pesticides.

More information about pesticides

Pesticides are found in	▪ Bug and weed killers used in homes, yards, farming, and landscaping. ▪ Insect repellants. ▪ Products to kill head lice. ▪ Products to kill fleas on pets. ▪ Termite and mosquito control.
Possible risks to people	▪ Some pesticides can affect hormone systems, reproduction, and brain development. ▪ Some pesticides can affect the kidneys and liver. ▪ Some pesticides can cause cancer.
Possible ways to reduce exposure	▪ Control indoor and outdoor pests with less toxic methods, such as bait traps. ▪ Wash fruits and vegetables. California tests samples of fresh produce for pesticides and takes action if the amounts are too high. For even less exposure, you can buy "certified organic" or "pesticide free" produce.

The *List of Pesticides Tested* in this packet gives more information about each chemical tested.

For More Information

Biomonitoring California **www.biomonitoring.ca.gov**

CDC National Biomonitoring Program **www.cdc.gov/biomonitoring**

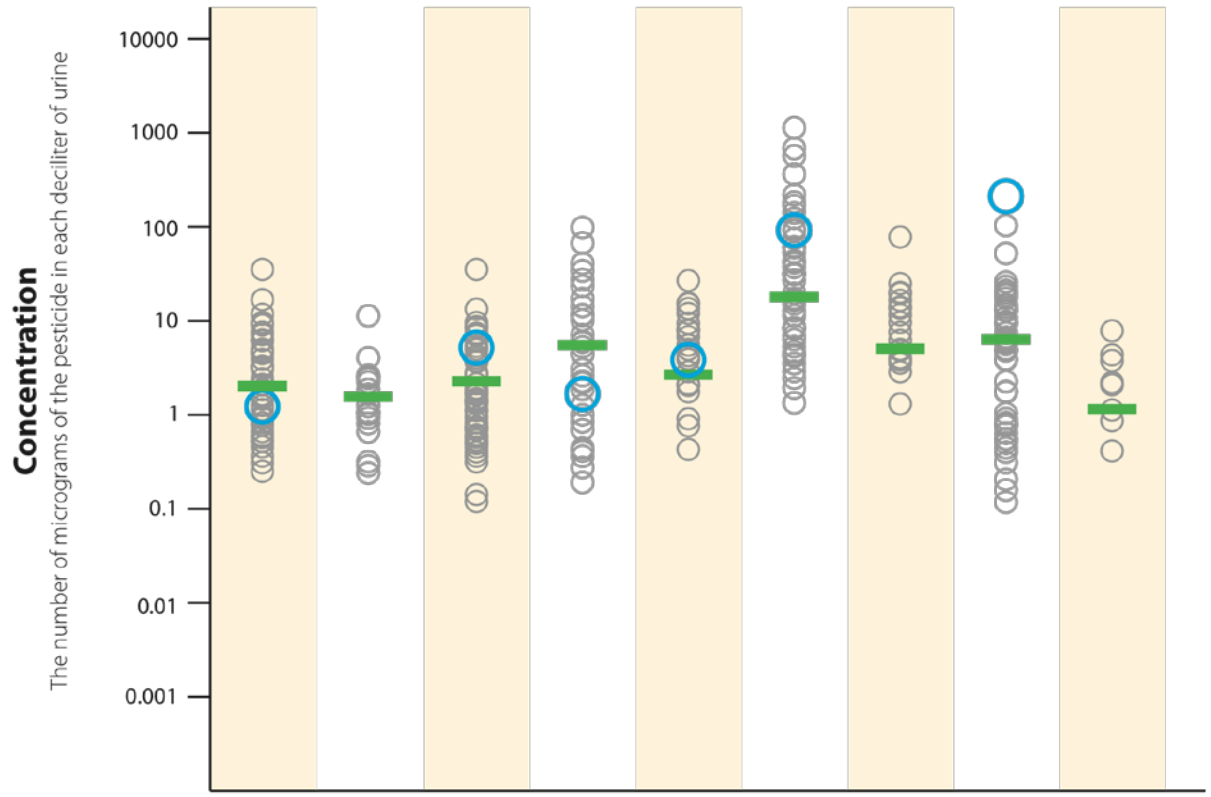
If you have any questions, please call the Project Coordinator, Jackie Schwartz, at 510-986-8925.

Part 2: Pesticides in Urine Results Chart

Participant number: 43

How to read this chart:

- **Your level** (There is no blue circle if we did not find this chemical in your sample.)
- **Other people's levels** Each circle represents a person in the study.
- **National average** The most common level for pregnant women in the U.S.



Pesticides	1. 3-PBA	2. OC	3. TN	4. DDT	5. DDE	6. DAPs	7. DEP	8. DMP	9. TCPy
Your exact levels	1.17	Not Found	7.92	2.32	5.40	105	Not Found	328	Not Found

For more information, see List of Pesticides Tested

Part 2: Pesticides in Urine

List of Pesticides Tested

This list tells you more about the pesticides shown on your Results Chart.

Chemical we tested	How is this chemical used?	Full name of the chemical we tested	The pesticide(s) you were probably exposed to
1. 3-PBA	**If we found this chemical in you, it means that you were exposed to certain pesticide(s). These pesticides are used in:** ▪ Pest control on livestock and in agriculture. ▪ Household insect sprays and repellants. ▪ Lawn and garden care products. ▪ Products to kill head lice. ▪ Products to kill fleas on pets. ▪ Termite and mosquito control.	3-Phenoxybenzoic acid (3-PBA)	cyhalothrin, cypermethrin, deltamethrin, fenpropathrin, permethrin, and tralomethrin (Pyrethroid pesticides)
2. OC 3. TN	**If we found these chemicals in you, it means that you were exposed to chlordane. Chlordane was banned in 1988. Before then, it was used on vegetables, fruits, lawns, and for termite control.** ▪ It lasts a long time and is found in animal fat. ▪ People are mainly exposed through fats in meat, fish, and dairy products.	Oxychlordane trans-Nonachlor	chlordane
4. DDT 5. DDE	**If we found these chemicals in you, it means that you were exposed to DDT or DDE. DDT was banned in 1972. Before then, it was used on agricultural crops and for mosquito control.** ▪ It lasts a long time and is commonly found in animal fat. ▪ People are mainly exposed through fats in meat, fish, and dairy products.	p,p′-DDT, o,p′-DDT p,p′-DDE	DDT or DDE
6. DAPs 7. DEP 8. DMP	**If we found these chemicals in you, it means that you were exposed to certain pesticide(s). In the past, these pesticides were used in homes and gardens, but these uses have mostly been phased out.** ▪ Now it is used for insect control in agriculture and for mosquito control.	Dialkylphosphates Diethylphosphate Dimethylphosphate	dichlorvos, malathion, and tetrachlorvinphos (Organophosphate pesticides)
9. TCPy	**If we found this chemical in you, it means that you were exposed to chlorpyrifos. Until 2000, chlorpyrifos was used for lawn care and to control household pests.** ▪ Now it is used for pest control in agriculture.	3,5,6-trichloro-2-pyridinol	chlorpyrifos (Organophosphate pesticide)

How Usability Testing Shaped Changes in Prototype Materials

1. Initial vs. Final Summary of Results for Metals

2. Initial vs. Final Results Chart for Metals

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INITIAL

Part 1: Metals in Blood

Summary of Your Results

We tested for 2 metals: lead and cadmium. We tested 85 mothers and their babies.

Your lead results: We found lead in your blood sample. We found lead in most mothers tested. Your lead level was higher than the average level for pregnant women in the U.S., and lower than the benchmark. Levels above the benchmark may be a health concern. We found lead in your baby's blood sample. We did not find lead in most babies we tested.

Lead is commonly found in	Possible risks to people	Possible ways to reduce exposure
▪ Peeling paint and dust inside and outside houses built before 1978 (when lead in house paint was banned). ▪ Metal water pipes in older homes. ▪ Jobsites in painting, construction, battery recycling, and radiator repair. ▪ Some consumer products: some old, imported, or handmade glazed dishes; some toys, art supplies, cosmetics, costume jewelry, hair dyes, medicines from China, and candies from Mexico.	▪ Can affect brain development and cause learning and behavior problems in babies and young children. ▪ Can cause high blood pressure, heart disease, kidney disease, anemia, reproductive problems, and memory loss in adults. ▪ Can cause miscarriage and low birth weight.	▪ Have a trained professional remove or cover old peeling or chipping paint. ▪ Vacuum and clean regularly. ▪ If you have lead pipes, use cold water from the faucet for drinking or cooking. Consider using a water filter certified to remove lead. ▪ Do not use old, imported, or handmade pottery for storing, cooking, or eating food, unless you know it does not contain lead.

- To have your home checked for lead, call the San Francisco Department of Public Health at 415-252-3956.
- For more information, go to **www.dhs.ca.gov/childlead**.

Part 1: Metals in Blood

Summary of Results for You and Your Baby

Lead

We tested for lead. Lead is a metal that is found in nature and is used in many industries and products.

Have you found lead in my blood or in the blood of my baby?

Yes. We found lead in you and your baby.

Can I compare my levels to other levels?

You can use the *Results Chart* in this packet to compare your lead levels to:

- **Other women and babies in the study.** We found lead in most mothers tested. Your lead level was lower than most mothers. We did not find lead in most babies we tested.
- **National average.** This is the most common level for pregnant women in the U.S. Your lead level was higher than the national average. The national average for babies is not known.
- **Level of health concern.** Levels above these may be a health risk. Your lead level was lower than the level of health concern. A level of health concern has not been set for lead in babies.

The next page explains more about lead.

More information about lead

Lead is found in	▪ Peeling paint and dust inside and outside houses built before 1978 (when lead in house paint was banned). ▪ Metal water pipes in older homes. ▪ Jobsites in painting, construction, battery recycling, and radiator repair. ▪ Consumer products: o Some old, imported, or handmade glazed dishes o Some toys, art supplies, cosmetics, costume jewelry, hair dyes o Some medicines from China o Some candies from Mexico
Possible risks to people	▪ Lead can affect brain development and cause learning and behavior problems in babies and young children. ▪ Lead can cause high blood pressure, heart disease, kidney disease, anemia, reproductive problems, and memory loss in adults. ▪ Lead can cause miscarriage and low birth weight.
Possible ways to reduce exposure	▪ Have a trained professional remove or cover old peeling or chipping paint. ▪ Vacuum and clean regularly. ▪ If you have lead pipes, use cold water from the faucet for drinking or cooking. Consider using a water filter certified to remove lead. ▪ Do not use old, imported, or handmade pottery for storing, cooking, or eating food, unless you know it does not contain lead.

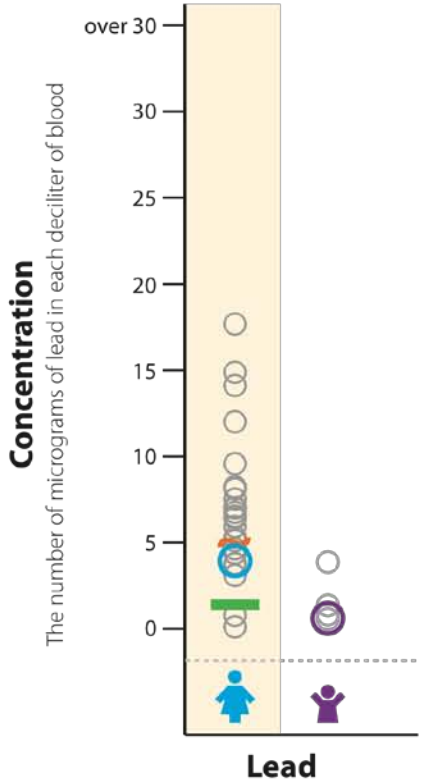
- To have your home checked for lead, call the San Francisco Department of Public Health at 415-252-3956.
- For more information, go to www.dhs.ca.gov/childlead.

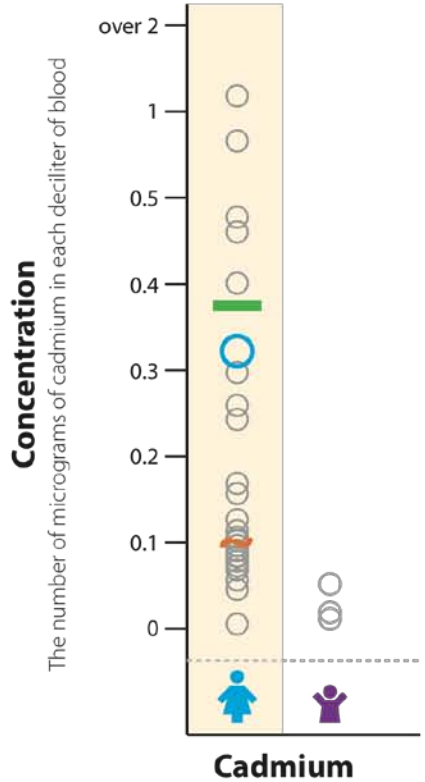
INITIAL

Part 1: Metals in Blood Results Chart

Participant number: 43

- **Your level** There is no blue circle if we did not find this chemical in your blood.
- **Your baby's level** There is no purple circle if we did not find this chemical in your baby's blood.
- **Other people's levels** Each circle represents a person in the study.
- **National average** in pregnant women.
- **Benchmark** Levels above this may be a health concern.





Your exact levels	3.85	0.98

Your exact level	0.326

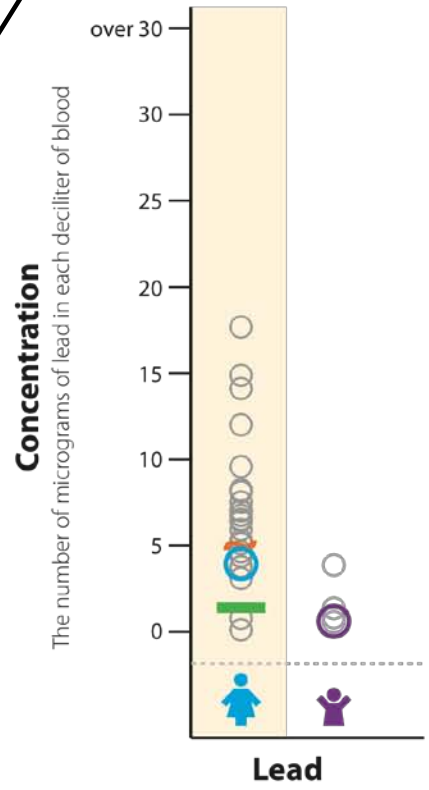
FINAL

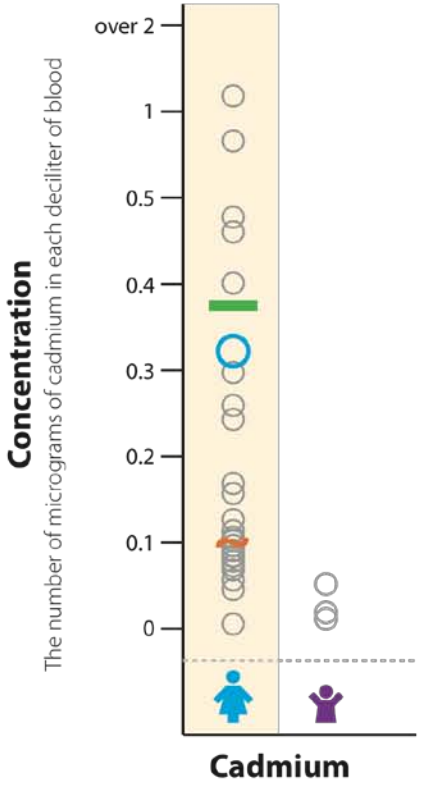
Part 1: Metals in Blood Results Chart

Participant number: 43

How to read this chart:

- **Your level** (There is no blue circle if we did not find this chemical in your blood.)
- **Your baby's level** (There is no purple circle if we did not find this chemical in your baby's blood.)
- **Other people's levels** Each circle represents a person in the study.
- **National average** The most common level for pregnant women in the U.S.
- **Level of health concern** Levels above this may be a health risk.





Your exact levels	3.85	0.98

Your exact level	0.326	Not Found

What Do Participants Think?

- Participants reacted favorably to materials.
  - Took 15-20 minutes to review
- View materials as a resource for family and future reference.
- Value seeing their results in comparison to other participants.
- Want context for comparisons and risk information, if possible.
  - Levels of health concern (if available) and national average
  - What's the difference and what do these mean?

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What Do Participants Think?

- Diversity of materials is important.
  - Some like charts
  - Some prefer text
  - Like option to drill down
- Actual chemical levels are less important.
  - Context of levels matters more
  - ‘High’ versus ‘low’
    - Compared to other participants
    - Average (need to define)

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Recommendations

- Documents are interconnected; make changes with care.
  - Small change in one necessitates changes in others.
- Maintain chapter format used in prototype organized by chemical class, with each chapter stapled as a unit.
  - Chapters allow for layering of information with option to drill down.
- Mix text with graphics.

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Recommendations

- Health literacy = biomonitoring literacy.
- We can enhance biomonitoring literacy by providing participants with transparent, accessible, useful, and comprehensive information.
- We recommend a health literacy review of the final materials to make sure information is as clear as possible.

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For More Information

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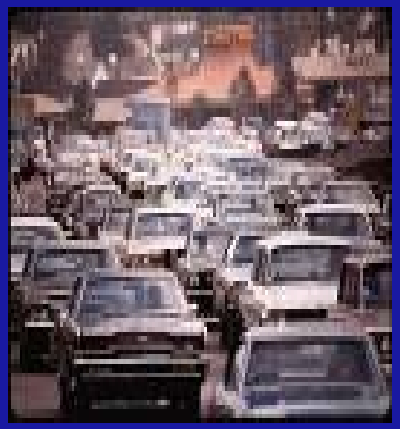
Thank You