

LAY ABSTRACT

TITLE: Researcher and Institutional Review Board Perspectives on the Benefits and Challenges of Reporting Back Biomonitoring and Environmental Exposure Results

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There is a growing number of scientific studies that measure chemicals in people's bodies (using blood, urine, or other bodily samples), households, and communities. Participants in these studies often want to know their personal results (for example, the number of chemicals detected in their body) even though researchers cannot always tell them exactly what the results mean for their health. Because of the uncertainty about health effects, some researchers and IRB members have questioned whether it is wise to return personal results. Others are adopting report-back as integral to the ethics of open communication and co-ownership of data in community-based participatory research. To explore different perspectives on this issue, we interviewed 17 researchers and 9 representatives from university ethics boards across the U.S. to learn about their

experiences with reporting back personal results. Researchers stated many benefits, including increasing public participation in research; improving study participants' knowledge about chemicals in their environment and health risks; helping participants, governments, and industries take actions to reduce chemical exposures; and aiding researchers in identifying important exposure sources through consulting with participants. Researchers also reported challenges, including keeping in touch with participants over long study periods, ensuring report-back materials are easily understandable and relevant, a lack of funding and time, and establishing procedures to notify participants of high exposures to chemicals (for example, what counts as a "high" result for a chemical without an established health guideline?). Interviewees from university ethics boards were primarily worried about participants being very anxious about their personal results. In contrast, researchers who have experience reporting back personal results said that participants generally do not appear alarmed and noted that worry can help inspire people to reduce their harmful exposures. There are still ethical issues that require further attention. For example, what is the responsibility of researchers to help participants and communities reduce their chemical exposures? What are productive ways to report back results to participants who might face challenges, such as poverty, that limit their ability to reduce personal exposures?