LAY ABSTRACT

TITLE: Comprehension and Perceptions of Study Participants upon Receiving Perfluoroalkyl Substance Exposure Biomarker Results

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Researchers often want to know how much of a chemical is in a person's body to determine if it is related to health problems. To do this, they look at how much chemical is in a person's blood or urine. We call this a "biomarker." Many people believe that when researchers measure biomarkers, they should tell the person how much chemical was there. But, we do not know if the people in research studies want to know this information.

We gave back biomarkers numbers to people in three different research studies. We then asked them what they thought about getting their numbers back. We did this by sending their numbers and a survey in the mail. We asked them to send back the survey to us. These people were all in research studies involving a chemical called "perfluoroalkyl substances." They all lived in the Ohio River Valley. Some of the people were telling us what they thought about getting their own biomarker numbers and some of them were telling us about getting the numbers for their children.

We got back completed surveys from 273 people. Almost all of the people who sent the survey back said they were glad that we mailed them their biomarker numbers. They also felt like they could understand the biomarker numbers. In the mailing packet, we included an information sheet about the perfluoroalkyl substances to help them understand the numbers. Most of them thought that this information sheet was helpful too. We were worried that this mailing might have too much information in it, but most of them thought that it had just the right amount. About half of the group was surprised at their numbers. They thought the number would be either higher or lower. People with high numbers were good at figuring out their numbers were high, which means they were able to understand their exposure level. Most people with low numbers did not realize their numbers were low. Most of them said that they did not tell anyone about their numbers. They did not tell friends, family, or their doctor.

In the future, researchers should:

- Keep giving people in research studies their biomarker numbers, because most of them were glad to receive them
- Provide information with the numbers to help explain what the biomarker numbers mean
- Ask why people do not like sharing their numbers with family, friends, and doctors