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Comprehension and perceptions of study participants upon receiving perfluoroalkyl substance exposure biomarker results

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ABSTRACT

Background: Measurement of environmental biomarkers in biomedica is increasingly used as a method of exposure characterization in human population studies. Reporting the results of biomarker measurements back to study participants has been controversial, including questions of ethics and whether the study participants would want to receive and would understand the results.

Methods: Recently we mailed individual measurements of two serum biomarkers, perfluorooctanoate (PFOA) and perfluorooctane sulfonate (PFOS) to participants in three exposure studies of persons living in the Ohio River Valley, of whom 60 were parents of children who had been sampled. Many had serum concentrations of PFOA above the US population 95th percentile value. Reporting forms used in the three studies were somewhat different (either tables or charts for comparison to US population values) and varied in complexity. With all reports, we included information about concentrations of PFOA and PFOS in the general population, and a survey designed to ascertain the opinions of the study participants about the information they received.

Results: Approximately 33% (273/821) returned the survey, and of those, 96% reported that they were pleased that we had sent them the report. Most (86%) responded that the results were easy to understand and the enclosed fact sheet was helpful in answering questions (87%). Regarding the amount of information, most felt that we provided the “right amount” (78%) but some “too much” (7%) and some “too little” (15%). The majority (53%) were surprised at their serum concentrations. Of those with serum values > 13.0 ng/mL, 74% responded that they thought their serum concentration was “high”, but only 22% of those with serum concentrations ≤ 5.6 responded that their concentration was “low”. Surprisingly, many talked to no one about their levels; those who did were most likely to discuss the report with family members.

Conclusions: Reporting back individual environmental biomarker results is generally well received by study participants, and those with high concentrations perceived them to be high. Questions remain as to why study participants did not discuss their results with others.

1. Background

Measurement of environmental biomarkers in biomedica is increasingly used as a method of exposure characterization in human population studies. Reporting the results of biomarker measurements back to study participants has been somewhat controversial. Ethical questions include whether results should be reported when there are no established health guidelines and whether all or selected results should be reported. Furthermore, many have questioned whether participants want to receive or would be able to comprehend this information (Exley et al., 2015; Lakind et al., 2008).

Report back protocols vary significantly between studies, and the amount of community involvement in developing protocols also varies (Brody et al., 2014; Exley et al., 2015; Morello-Frosch et al., 2009). Several studies have addressed the community engagement process for developing the method of returning results (Haynes et al., 2016), the best format for the actual report (Boronow et al., 2017; Lakind et al., 2008; Morello-Frosch et al., 2009), or the resulting changes in behavior (Wu et al., 2009). Community meetings to return results may increase participant understanding but often reduce the number that receive the information due to low attendance (Wu et al., 2009). Although others have studied participant's preferences for the report format or impact

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on behavior, to our knowledge, no study has administered a structured questionnaire after returning individual results to a large population.

Morello-Frosch et al. conducted interviews with scientists and participants involved in biomonitoring studies and identified key components to include when reporting results. They suggested providing context for information to help participants interpret their individual results, and specifically giving individual results in the context of aggregate study results rather than population results which may be more abstract to the participant (Morello-Frosch et al., 2009; Quandt et al., 2004). Including reasonable steps for exposure reduction, with an emphasis on including those interventions whose effectiveness had been established, may also be helpful (Morello-Frosch et al., 2009). Other studies have highlighted the importance of addressing literacy including public health and environmental literacy (Ramirez-Andreotta et al., 2016). Haynes et al. reported back individual biomonitoring results by using an iterative approach to develop different ‘data disclosure’ strategies. At each iteration, community partners were involved in giving feedback on the communication. For example, community members explained that displaying results on a blood tube image was easier to interpret than displaying on a data plot. After results were reported back, participants were surveyed and all 30 participants indicated that the images and factsheets were helpful (Haynes et al., 2016). Other studies have examined the impact of reporting results on behavior. Participants who received individual biomonitoring results from breastmilk samples reported that they did not alter their breastfeeding duration, mostly due to “breastfeeding is best” message that was delivered along with results (Wu et al., 2009). This highlights the importance of giving results in the context of current health recommendations, known health effects, and effectiveness of exposure reductions (Arendt, 2008).

In this study, we returned results of individual biomarker measurements to participants in three different study populations and then administered a structured questionnaire to ask about the effectiveness of the communication and the effect on their behaviors. Here we report the findings of a data analysis of 273 respondents.

2. Methods

We mailed results of individual measurements of two serum biomarkers, perfluorooctanoate (PFOA) and perfluorooctane sulfonate (PFOS) to participants in three perfluorinated alkyl substance (PFAS) exposure studies of persons living in the Ohio River Valley. For each study, enclosed with the mailing was a survey to obtain information about how the biomarker results were received by the study participants.

2.1. Study cohorts and PFAS concentrations

The first study was of a cohort of girls transitioning through puberty (PUB study), begun in 2004 (Cincinnati Children’s Hospital Medical Center IRB, 2008–0170) (Biro et al., 2010). Baseline PFAS serum concentrations were measured in serum samples obtained between February 2005 and December 2006 (81%), but some as late as October 2007 (Pinney et al., 2014). The decision to report back was reached after input from the breast cancer advocate community, and we collaborated with our advocate advisees on the design of the form (Hernick et al., 2011). We initially mailed results to a small number of parents in 2007 (living in the community with the highest values) but did not include the survey. In 2013 (after publication of the Hernick, 2011 manuscript) we mailed results to the remaining 260 parents or guardians of the girls and included the survey. The PUB study consent form included a general statement that study participants would receive health results and did not specifically mention environmental biomarkers. Prior to the 2013 mailing of results we obtained feedback on the proposed form from our parents’ advisory group, the IRB, and health care professionals at Cincinnati Children’s Hospital Medical Center,

resulting in a form design that was somewhat different from the 2007 form.

The second study was a cross-sectional study of a convenience sample of persons living in Huntington, West Virginia, Portsmouth, Ohio, and the greater Cincinnati area (Ohio River Valley or ORV study), including 60 who were parents or siblings of the girls in the PUB study (UC IRB 08-06-16-01 EE) (Herrick et al., 2017). We recruited persons whose primary drinking water source was either artesian well water or the Ohio River, delivered by water treatment plants in their geographical area. Serum samples were obtained over two years, 2009 to 2011, and results were mailed at several time points from 2009 through 2012. There were 366 total participants in the ORV study but only 351 mailings were sent. For mother-child dyads of study participants, only one survey was sent per family. We did not collect education information from the ORV group as this was a one-time encounter, cross-sectional exposure assessment study.

The third study was conducted with a sub-cohort of selected members from the Fernald Community Cohort (FCC) (Fernald Community Cohort website, 2012; Wones et al., 2009). Established in 1990, this large longitudinal cohort consisted of persons living within five miles of a uranium refinery for at least two years from 1951 to 1984 (UC IRB, 2012–3745). Participants in the PFAS exposure study were a sub-cohort of the original Fernald cohort, and eligibility was based on having lived in towns upriver from Cincinnati Ohio or in northern Kentucky at some time after 1980 until the time of data collection in 2012 (Herrick et al., 2017). Serum biobanked from 1990 to 2008 was used for PFAS measurements, with two or more measurements per person. Results were mailed in 2013–2014. Many of the study participants had serum concentrations of PFOA above the US population 95th percentile value, first discovered in 2013 when we received the first laboratory reports from the CDC Environmental Laboratory. Not all participants who were consented for the FCC PFAS exposure study ultimately had sera sent for measurement; 275 were consented and 210 had serum samples submitted for measurement (and received results) because there were insufficient funds for repeated measures of PFAS biomarkers on all 275 participants. We consulted the long established advisory group of the FCC in the design of their report back forms.

Consent forms for the ORV and FCC studies directly asked participants if they wished to receive their individual environmental biomarker results with “yes” and “no” response choices. No incentive for returning the survey was offered to any of the study participants.

2.2. Report format development

Mailings were designed through a collaboration of investigators, community advocates and community physicians, with the goal of helping the participants to understand their results yet not to overwhelm them with the amount of information provided. We sent a mailing to participants of all three studies that included the following items: 1) a personal reporting form of their environmental biomarker result; 2) information about concentrations of PFOA and PFOS in the general population; 3) a fact sheet about PFOA and 4) a survey with a postage pre-paid return envelope.

Reporting forms were pre-tested using a small number of community members who were not participants in these PFAS studies, and differed depending on the feedback we received from the community members. Forms underwent multiple levels of review, including with community members and the Institutional Review Board (IRB). We used a mail merge function in word processing to facilitate producing forms populated with names and individual biomarker concentrations (Figures S1–S3). Also, we had two staff members compare the generated forms to the original data sheet to ensure we were sending the correct results. The personal reporting forms used for each of the three studies included the NHANES population median and 95th percentile values of the biomarker concentration relevant to the study population and the

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