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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 biomedicine 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.

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Appendix A. Supplementary data

Supplementary data related to this article can be found at <https://doi.org/10.1016/j.ijheh.2018.07.005>.

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.

Keywords

Perfluoroalkyl substances; Biomonitoring; Report back

1. Background

Measurement of environmental biomarkers in biomedicine 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 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 year of serum sample collection (Centers for Disease Control and Prevention, 2018). We used the median and 95th percentile values for children ages 12–19 for 2005–2006 for the PUB study. For the ORV study, we used the

NHANES reported values for all adults 2003–2004, and for the FCC study, we used the NHANES values for 1999–2000 for all adults, the earliest time points reported. The reporting form for the PUB study also included a chart with a narrative explanation that compared the individual's serum concentration to that of the study population and other populations (Figure S1). Although the PFAS assay panel includes multiple analytes, only values of PFOA and PFOS were reported. Biomarker concentrations of the other analytes were low; almost all values were below the NHANES study 95th percentile level. The decision to include only two analyte concentrations was made to prevent confusion after discussion among the investigators and community advocates.

We included a fact sheet published by the Ohio Department of Health on perfluorochemicals (Figure S4) (Ohio Department of Health, 2012). We also developed a frequently asked questions (FAQs) sheet in anticipation of calls to study personnel after the mailing, so that our replies would be standardized.

2.3. Survey development

The survey included in the mailing was designed to ascertain the opinions of the study participants about the information they received (Figure S5). It asked whether the participant was pleased to have received the report, whether the report was easy to comprehend, and what actions they took after receiving their report such as changing drinking water source or discussing results with other people. The survey for the FCC study also included a question that ascertained whether study participants correctly perceived their individual results in comparison to the aggregate data we gave them. In order to reduce participant burden, the survey was limited on one or two pages, and most response categories were either Yes/No or two to four narrative options.

2.4. Statistical analyses

Survey data were entered and verified; descriptive statistics were generated in SAS (SAS 9.2, SAS Institute, Cary, NC). Descriptive statistics were calculated by study for age, gender, education of participant or parent reporter of a minor participant, and serum concentrations of PFOA and PFOS, testing for differences in continuous data using Student's t-test and Chi-square test or Fisher's exact test for categorical data. For some analyses, we stratified responders by educational attainment level, high school graduate (HS) versus > HS, for only the FCC and PUB study groups. For the FCC study group, we categorized PFOA serum concentrations as "low" (< 5.6 ng/mL); "medium" (5.6–13.0 ng/mL); and "high" (> 13.0 ng/mL) based on median and 95th percentile values for the 1999–2000 NHANES study population, since the serum samples in this study were collected as early as 1990 (Centers for Disease Control and Prevention, 2018). A Kappa statistic was calculated to determine the agreement between actual PFOA levels that were categorized as "low"/"medium"/"high" and the perception of the participants, as indicated by the response to an item on the questionnaire (Landis and Koch, 1977).

3. Results

3.1. Response rate

Of the participants consented for the ORV and FCC studies, only 4 opted out of receiving their biomarker results on their consent form. PUB study participants were never specifically consented to receive biomarker results. Personal biomarker results and the survey were mailed to 821 participants and or guardians of minor participants; 33% (N = 273) returned the survey. Response rates for individual cohort populations were ORV 32% (111/351), PUB 23% (59/260), and FCC 49% (103/210). Responders and non-responders of the three studies combined, and the individual studies, did not differ by age at sample or mailing, race or education level. The median PFOA values for responders in the OVR study was significantly higher than ORV non-responders, but there was no difference in median PFOA for the other two studies and no difference for PFOS (Tables 1 and 2).

There were some differences in characteristics of responders across the three studies. FCC responders were older at the time of the mailing than ORV responders ($p < 0.0001$), and more likely to be male ($p = 0.007$). The PUB study had significantly more African-American responders ($p < 0.0001$), and, when compared to the FCC study participants, had a greater proportion with educational attainment beyond high school ($p < 0.0001$). Reported serum concentrations of both PFOA and PFOS were significantly higher in the FCC study ($p = 0.0001$).

3.2. Information in mailing

Of those that responded, 96% reported that they were pleased that we had sent the report. They reported that the results were easy to understand (86%) and the enclosed fact sheet was helpful in answering questions (87%). Although the FCC report back form was more complex than the others, the respondents from that study were just as likely to affirm that the results were easy to understand (88%) as the other two studies (ORV, 86% and PUB, 83%) (Table 3).

Participants were asked about the amount of information they received in the mailing. While 78% responded that they received the “right amount” of information, 15% responded “too little”, and 7% responded that there was “too much” information provided. The percentage of respondents who felt they received too little information differed by cohort; 18% of FCC participants and 23% of PUB participants, compared to only 3% of ORV participants (Fisher’s p value = 0.003). Responders reported that the tables (90%) and fact sheets (87%) included with their results were helpful in answering questions and in understanding the results (Table 3). For both the PUB and FCC studies, there was no difference in responses by education level for questions asking about the amount of information, ease in understanding information, or whether the charts and tables were easy to understand. Fisher’s exact test p values ranged from 0.2 to 1.0. Fifty-three percent were surprised at their serum concentrations (Table 3), and this proportion did not differ by education level in either PUB or FCC studies. The percent of missing data for these question responses ranged from 1.1% for the question “Were you pleased” to 7.3% for the question asking about being surprised by the serum concentrations. Early versions of the questionnaire sent to the ORV

study group did not include this question. There was no education information available for ORV study participants.

3.3. Change in water source use

Participants were asked whether they would make any changes in their drinking water habits after receiving their PFAS results, and 38% indicated that they would be making changes. Those in the FCC were less likely (17%) than either PUB (63%) or ORV (46%) (X^2 p value, 0.001) (Table 3); 7.3% did not answer this question. There was no difference in this response by education level in the PUB and ORV studies. When results were stratified by adults responding to the survey for themselves compared to a parent responding to the survey on behalf of their minor child (younger than 18), there was a notable difference. More parents (63%, PUB study) reported that they would change drinking water habits compared to adult participants (39%) in the other two studies. All but seven of the 67 minor participants were part of the PUB study.

3.4. Sharing results with others

Forty-nine percent of participants did not discuss their reports with anyone; those who did were most likely to discuss the report with family members (38%) (Table 3). Of the 107 persons with PFOA serum concentrations above 13.0 ng/mL, only 11 reported that they discussed their results with a health care provider. Very few contacted the study personnel with questions.

When the respondents were stratified by age, study population, gender and parent vs. adult population, no additional differences were found between study groups.

3.5. Comprehension of individual environmental biomarker results

To measure comprehension of individual environmental biomarker results, FCC participants were asked if they thought their results were “high”, “medium” or “low”, and their responses were compared to categories of their actual levels, using cut points equivalent to the median and 95th percentile values of the with 1999–2000 NHANES population (Table 4). A Kappa analysis found the agreement to be “moderate,” at 0.388 (95% CI: 0.257–0.521). It was easiest for responders with high levels to correctly interpret their serum concentrations as “high” and for responders with low serum concentrations to correctly interpret their results as “not high”. For example, of respondents with high serum PFOA levels, defined as > 13.0 ng/mL, 74% perceived their results to be “high”. For respondents with low serum PFOA levels, defined as 5.60–13.0 ng/mL, none perceived their results as “high”. Interpretation was most difficult when distinguishing between medium and low ranges. Among respondents with medium levels, 39% believed that their values were “low” and among respondents with low values, 78% believed that their values were “medium.” In sub-groups stratified by attained education level (HS vs.>HS), the agreement was better for the >HS group (Kappa=0.476) than the HS group (Kappa = 0.251).

4. Discussion

To our knowledge, this is the first large study to administer a structured questionnaire following report back of environmental biomarker measurements, to gather perspectives on receiving individual environmental biomarker results and ascertain the comprehension of the results. We found that reporting back individual environmental biomarker results is generally well received by study participants, and learned that few recipients discussed their results with others.

In our studies, participants were provided their individual environmental biomarker results, along with a comparison to national levels (NHANES data) and other information about the chemicals of interest, PFOA and PFOS. These mailings were designed with the goal of providing sufficient information to help the participants interpret their results, yet not overwhelming them with information. Interestingly, some responders in the FCC study (18%) and the PUB study (28%) felt that too little information was provided in the mailing. Both studies are longitudinal cohorts, and participants had past experience receiving results from investigators and playing active advocate roles in environmental exposure research. Their experience may be why they felt comfortable with more information, although this was the first time we sent this group of participants environmental biomarkers results. In line with previous studies, responders felt that the additional information (Figure S4 - fact sheet) was particularly helpful (Haynes et al., 2016; Morello-Frosch et al., 2009). Responders to the survey were generally good at correctly interpreting high results, but there was some confusion in distinguishing between the middle and low categories. It may have been easier to interpret extreme values than interpreting values between two thresholds ($5.6 \text{ ng/mL} < x < 13.0 \text{ ng/mL}$).

More parents who were responding to the survey on behalf of their minor children indicated that they would change drinking water habits after learning results of the biomarkers as compared to adults responding to the survey for themselves. This could also be a study population effect; almost all of the minors arose from the puberty cohort population. Parents could have felt that preventative actions were more important in children who were still developing compared to adults. FCC responders were least likely to indicate that they would change drinking water habits (17%), but for this study group, many changes in drinking water habits related to uranium contamination had occurred in the past (government supplied bottled water, followed by new public drinking water service to many areas).

A low number of respondents discussed their environmental biomarker measurements with others. The reasons for this are unknown as this study did not qualitatively assess why participants decided to share this information or not. There may have been limited opportunity. The survey was sent with the reports, so respondents may have immediately completed and returned the survey, allowing little time to discuss with others, particularly health care providers. Another potential reason may have been participants' perception of the results to be similar to medical test reports, and therefore not have deemed it appropriate to discuss with friends or neighbors. Participants may have felt that they lack the vocabulary and familiarity with the chemicals, inhibiting discussion particularly since the chemical names were unfamiliar and difficult to pronounce. Although few reported discussing results

with others, there are potential benefits of this exchange. Discussion of results with health care providers could be effective in reducing anxiety over high results, and sharing the information with a physician could result in greater awareness of the community profile of environmental exposures. Participants also did not call investigators to discuss results nor did we hold community meetings afterwards. Community meetings may have provided a better opportunity for exchange of information about perfluoroalkyl substance exposure but we decided against such meetings because of previous experience with low attendance at similar meetings. Community awareness and action, however, are most likely to come out of a community discussion of the exposure.

The primary limitation was the low survey response rate, although responders were not substantially different from non-responders on all characteristics except level of PFOA and PFOS serum concentration. The overall response rate was 33%, and especially low in the PUB study. This study has several strengths, including large sample size and use of the same survey instrument on three different study populations. Overall, responders were quite positive toward the information in the packet, but those who were more positive may have been more likely to respond. Modifications may need to be made in the future to strengthen the level of understanding among participants whose PFAS or other chemical levels are in the low and medium ranges. Obtaining information on health literacy or health numeracy was beyond the scope of our study but limited our interpretation of the findings, although we were able to stratify analyses on level of education. In all study groups, participants were more likely to complete the questionnaire if they had higher levels of PFASs, and this may have biased our results. Mailing the survey with the results may have led to some participants completing the survey at the time receiving results, with no time to discuss with results with family or health care professionals, leading to under-ascertainment of the frequency of these discussions. Use of qualitative data collection methods, especially interviews, may have captured information from those with lower literacy levels, providing better insight into their comprehension.

The cost in effort and dollars of reporting back results should not be underestimated. Significant effort was required to design and pretest the reporting back forms, and they underwent multiple levels of review. Engaging community members and physicians in this process always results in a more appropriate communication instrument but increases the time for the process. Using a mail merge function to automatically produce report forms provides the benefit of individualized forms, but there was a significant time burden associated with two research staff members checking each printed form. While this quality control was necessary, it increased reporting burden. As expected, some mailings were returned by the post office, which required additional effort to find a current address for the study participant.

Through our investigation we learned that almost all study participants consented to receiving individual biomarker results, and of those who returned the survey, almost all were pleased to have received the information. Most responders with high levels of the biomarkers were able to interpret that their levels were high. This first analysis of quantitative data obtained via structured questionnaire provides foundational information for future studies of the effectiveness of communication of biomarker results and resulting

health behaviors. Future studies of this type should conduct data collection a few weeks after mailing results, collect information on health literacy and health, and use interviews to explore why results were not discussed with family and health professionals. Although the time and effort burden of reporting back is significant, the information transparency should increase the general public and health professional awareness of the prevalence of environmental exposures.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1

Demographics of responders to survey.

Demographic	Ohio River Valley Study		Puberty Cohort Study ¹		Fernald Community Cohort		All	
	N		N		N		N	
Number of responders	111		59		103		273	
Age at sample ² (mean/sd)	43.5 (16.5)		7.8 (0.8)		44.6 (14.4)		36.3 (20.3)	
Age at results mailing ³ (mean/sd) ±	44.5 (16.4)		46.6 (10.1)		62.0 (12.8)		51.6 (16.2)	
Female [*]	83 (75%)		59 (100%)		59 (57%)		201 (74%)	
Race [*]								
African-American	1 (1%)		19 (32%)		0 (0%)		20 (7%)	
White	107 (96%)		39 (66%)		102 (99%)		248 (91%)	
Other	1 (1%)		1 (2%)		1 (1%)		3 (1%)	
Education [#]								
Less than high school	–		2 (3.4%)		6 (5.8%)			
High school graduate	–		3 (5.1%)		39 (37.9%)			
More than high school	–		50 (84.7%)		55 (53.4%)			
Median PFOA serum concentration (ng/mL) ^{4**}	10.0		7.9		15.6		10.1	
Median PFOS serum concentration (ng/mL) ^{4**}	7.1		14.7		33		15.6	

Notes.

¹) All Respondents were parents or guardians of girls.²) Age at sample with highest PFOA concentration (FCC only); test of the difference in age at sample compared only ORV to FCC.³) Used age of mother of participant for minors (ORV and PUB).⁴) Median value of each person's sample with highest concentration (FCC).

± t-test, p < 0.001.

Fisher's p < 0.05.

* Chi square test, p < 0.01.

Non-parametric median test, $p = 0.0001$.

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Table 2

Demographics of non-responders to survey.

Demographic	Ohio River Valley Study		Puberty Cohort Study ^a		Fernald Community Cohort		All	
	N		N		N		N	
Number of non-responders	240		201		107		548	
Age at sample ^b (mean/sd)	39.6 (15.9)		7.8 (0.6)		41.8 (14.7)		28.3 (19.9)	
Age at results mailing ^c	40.4 (15.9)		44.8 (9.9)		59.9 (13.2)		45.5 (15.2)	
Female	167 (70%)		201 (100%)		70 (65%)		438 (80%)	
Race								
African-American	5 (2%)		81 (40%)		0 (0%)		86 (16%)	
White	225 (94%)		112 (56%)		107 (100%)		444 (81%)	
Other	6 (3%)		8 (4%)		0 (0%)		14 (3%)	
Education								
Less than high school	–		5 (2.5%)		11 (10.3%)			
High school graduate	–		15 (7.5%)		29 (27.1%)			
More than high school	–		172 (85.6%)		63 (58.9%)			
Median PFOA serum concentration (ng/mL) ^d	7.6		6.9		13.8		8.0	
Median PFOS serum concentration (ng/mL) ^d	7.1		12.8		30.7		11.8	

^a All respondents were parents or guardians of girls.^b Age at sample with highest PFOA concentration (FCC only).^c Used age of mother for minor participants (ORV and PUB).^d Median value of each person's sample with highest concentration (FCC).

Table 3

Survey results.

YES responses to items on questionnaire ¹	Ohio River Valley Study (ORV)		Puberty Cohort Study (PUB)		Fernald Community Cohort (FCC)		All	
	N	N	N	N	N	N	N	N
Total number of responses	111		59		103		273	
Pleased to receive results	108	97%	56	95%	99	96%	263	96%
Amount of information ^{2,†}								
Too much	8	12%	3	5%	4	4%	15	7%
Right amount	57	85%	41	72%	76	77%	174	78%
Too little	2	3%	13	23%	18	18%	33	15%
Results easy to understand	96	86%	49	83%	91	88%	236	86%
Charts/Tables easy to understand ³			50	85%	96	93%	146	90%
Fact sheets helpful ³			50	85%	91	88%	141	87%
Surprised by results	57	51%	34	58%	53	51%	144	53%
Expect to be higher ⁴	11	19%	7	21%	18	34%	36	25%
Expect to be lower ⁴	42	74%	24	71%	22	42%	88	61%
Making changes to drinking water habits [*]	51	46%	37	63%	17	17%	105	38%
Not sure	8	16%	0	0%	2	12%	10	10%
Water filter	24	47%	25	68%	7	41%	56	53%
Bottled water	24	47%	17	46%	10	59%	51	49%
Other	10	20%	8	22%	3	18%	21	20%
Discussed results with								
Nobody	70	63%	24	41%	41	40%	135	49%
Family	30	27%	23	39%	51	50%	104	38%
Friend	1	1%	14	24%	5	5%	20	7%
Neighbor	1	1%	1	2%	0	0%	2	1%
Health Professional	3	3%	2	3%	14	14%	19	7%

Notes.

^{1/}Column percent's do not sum to 100% because of missing data.

2) Question not asked on initial mailing to ORV, denominator includes only those asked.

3) Question not asked on ORV questionnaires.

4) Question only asked if “surprised by results”.

[‡] Fisher’s $p < 0.05$.

^{*} Chi square test, $p < 0.01$.

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Table 4

Agreement of actual and perceived serum concentration of PFOA in the Fernald Community Cohort (FCC) Study participants.

Perceived level of serum PFOA	Actual PFOA Serum Concentration						Total	
	Greater than 13.0 ng/mL		5.60–13.0 ng/mL		Less than 5.60 ng/mL		N	%
	N	%	N	%	N	%		
High	37	74%	4	11%	0	0%	41	43%
Medium	4	8%	18	50%	7	78%	29	31%
Low	9	18%	14	39%	2	22%	25	26%
Total	50	100%	36	100%	9	100%	95	100%

K=0.388 (95% CI: 0.257–0.521).

Unweighted “moderate”.