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Development and Successful Application of a “Community-First” Communication Model for Community-Based Environmental Health Research

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Abstract

Objectives—Effectively communicate results from a community exposure study to meet predetermined community priorities, maintaining ethical principles of autonomy, empowerment and justice.

Methods—The community established principles for the communications and a plan to inform study participants, community and other stakeholders of results and recommendations in a novel sequence: the “Community-First” communication model.

Results—The communications resulted in positive actions including company sponsored free bottled water, accepted by 77.6% of eligible households. Over 95% of participants in a follow-up survey had made some change to residential water supplies. Serum PFOA levels were reduced. Government agencies acted on the results.

Conclusions—The unique communication approach generated workable solutions to the problem investigated, raised community awareness and modified behaviors. Information generated a “free market” of community-level solutions. Each major stakeholder voluntarily adopted a “precautionary principle”.

INTRODUCTION

Risk management for environmental health hazards has the goal of implementing scientifically sound, cost-effective, integrated actions that reduce or prevent risks while taking into account social, cultural, ethical, political, and legal considerations.¹ Risk is increasingly measured and managed outside of government arenas by individual citizens, local businesses, workers, industries, farmers, and fishers. Because both regulatory and voluntary approaches may reduce risk, a variety of stakeholders need to be informed,

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involved, and motivated.² Motivation might be enhanced by publicly-funded, independent research that avoids the potential bias and suspicion attendant on research funded by those with commercial interests in the results, and by community participation in the research process through community based participatory research (CBPR).³

CBPR integrates rigorous investigator-led research to answer scientific questions, and community involvement to ensure the right questions are asked and to empower those affected by providing information necessary for informed action.⁴ This format should improve translation of research into favorable action. CBPR can be particularly appropriate for environmental health research addressing the exposure and potential effects of toxicant exposure: community members are often well motivated to participate in such research. Risk may be reduced either by actions by individuals or by collective actions such as support for improved chemicals policies and practices. Since environmental pollution and toxicant exposure disproportionately affect low-income US communities, CBPR could help reduce the accompanying information and resource disparities.⁵ CBPR supports two objectives of the US Executive Order on Environmental Justice: ensuring greater public participation in affected communities and improving research and data collection.^{6,7}

Motivating individuals or organizations to change behaviors requires clear, credible, and persuasive communication of research results. Where research involves health-related observations on individuals, dissemination of research results should include reporting of personal findings, as well as reporting of group results to the wider interested communities. While joint study design and implementation are well-described features of CBPR, there is a relative dearth of successful models integrating the dissemination of results and recommendations to both the interested community and participating individuals. Since CBPR may be most applicable where there are information disparities requiring direct translation of research results to community stakeholders, effective and acceptable communication of results can be of paramount importance.

CBPR typically incorporates the community to ensure that the appropriate questions are asked and that the interests of the community are considered during conduct of the research. Reporting the research results to the community may use the traditional scientific pathway in which results are published in scientific journals and then translated for the community through articles written by scientific journalists in the lay media. Despite the importance of peer review, a paternalistic “trickle-down” communication model is at odds with the principle that CBPR research involves an equal partnership between the community and scientific researchers, with an emphasis on community empowerment.

In this paper we describe the success of a novel approach to the communication of results of a study conducted by a community-investigator research partnership. We investigated human exposure and potential health effects from pollution from PFOA in rural Appalachian Ohio. We developed a set of principles reflecting the wishes of the community to govern communications. Using these principles we jointly developed and implemented a detailed strategy to communicate the results sequentially to studied individuals, the community as a whole, and other interested stakeholders. The community response included both implementation of our recommendations, and a set of unexpected positive actions by several parties based on the information communicated. These actions collectively resulted in successful reduction of the potential hazard.

STUDY BACKGROUND AND CONTEXT

Details of study background, methods and results have been published and should be consulted for further details.^{8,9} Only issues particularly related to the communication strategy will be described in this paper.

PFOA in Community Water Supplies

Little Hocking is a small rural community along the Ohio River, in Washington County, one of 12 counties officially recognized as Appalachian Ohio. The mean per capita income and per capita market income are lower, and the unemployment rate higher for Washington County than for either the United States or Appalachia as a whole.¹⁰ Upwind and across the Ohio River from Little Hocking is a fluoropolymer production facility, located in the state of West Virginia, where Ammonium Perfluorooctanoate (APFO) has been used since 1951 as a surface-active agent in the manufacture of TeflonR. APFO was released from the facility to air and groundwater and disposed in local landfills. APFO readily dissolves in aqueous solutions to form perfluorooctanoate (PFOA) which persists in the environment and does not hydrolyze, photolyze, or biodegrade under environmental conditions.¹¹ Although PFOA does not occur in nature, it is now found in biota worldwide. PFOA enters the human body through inhalation or ingestion. Within the human body it is very persistent and has a half-life of approximately 3.5 years.¹² PFOA is detectable in the 3.9 ppb range in blood in the general US population.¹³ Exposed fluorochemical industry production workers have significantly higher levels.¹⁴ According to the EPA, prior to our study the sources for PFOA in non-occupational populations were entirely unknown.¹⁵

PFOA is markedly toxic to the liver in rodents and carcinogenic to rats¹⁶, although the mechanisms responsible for hepatotoxicity and carcinogenesis in rodents may not apply in humans. The USEPA Science Advisory Board recently concluded that PFOA is probably carcinogenic to humans.¹⁷ PFOA can cause delays in both general and sexual development in rodents.^{18,19} Surveys of occupationally exposed workers have shown effects on blood chemistries in some but not all groups studied. A retrospective occupational cohort mortality study showed an increased risk of prostate cancer²⁰, not observed when the study was repeated with smaller exposure groups.²¹ Prior to our study there was no data on health effects in the general population.

During 2001, PFOA was found in water samples from the public water supply source wells of the Little Hocking Water Association (LHWA). These levels, ranging from 0.855 ppb to 7.69 ppb, were considerably higher than any reported public water supply, and created great community concern. LHWA serves approximately 12,000 people in over 4,000 households. The water comes from wells near the Ohio River opposite the fluoropolymer production plant. PFOA was subsequently also detected in private residential water wells in the area. As a result we formed the partnership that initiated the study and communications described in this paper, destined to be the first published study of community PFOA exposure.

Community Skepticism

The announcement, widely reported in the local media, that community water supplies were contaminated with PFOA heightened community concern and skepticism as described in a book about the situation written by a resident in the area.²² Prior to the initiation of our study in September 2003, a request from the LHWA to have independent measurements of PFOA in their water was refused by a leading laboratory, citing commercial relationships (LHWA, oral communication) and local newspaper articles²³ reported claims that PFOA was found in LHWA tap water samples from 1984 but neither authorities nor the community had been informed. At the same time, 3M Corporation announced it would stop the

manufacturing of PFOA²⁴ and sent a Substantial Risk Notice to the U.S EPA²⁵ citing potential reproductive and developmental hazards. The U.S.EPA initiated a “priority review” of PFOA given concerns about reproductive/developmental toxicity, carcinogenicity, and blood monitoring data. The State of West Virginia and others adjusted the “safe levels” of PFOA increasingly higher, seemingly, from the communities’ perspective, to remain above the highest level detected in LHWA wells. Following measurement of PFOA in LHWA wells up to 78 ppb, the State of West Virginia pronounced the “safe level” as 150 ppb,²⁶ far above the historic internal Community Exposure Guideline of 1 ppb in water used by the fluoropolymer facility, and well above an interim action level of 14 ppb established by a USEPA Consent Order with the company. The West Virginia “safe level” was criticized as seriously flawed by the Environmental Working Group.²⁷ Local newspaper polls reported that over 2/3 of residents remained “still concerned” or “very worried” despite the higher “safe level”.²⁸ A class action suit was initiated.

Collectively these developments eroded the credibility of both government and the fluoropolymer facility in the affected community.

METHODS

Participatory Partnership Model

We formed an Environmental Justice Partnership, as defined by the National Institute for Environmental Health Sciences (NIEHS), between environmental health researchers at the University of Pennsylvania School Of Medicine, a local health care provider, and the Decatur Community Association, a community association of residents living within the LHWA district, to conduct an independent scientific study addressing community concerns regarding PFOA. The local health care providers (H.Z and N.R) had been residents in the external Occupational Medicine practicum year training program we have previously described.²⁹ The partnership adopted the general risk assessment and management framework from the Presidential/Congressional Commission on Risk Assessment and Risk Management.¹ The framework has successive phases of: defining problems and putting them into context; assessing and analyzing risks; analyzing options; making a decision; taking action; and evaluating results, all with stakeholder engagement and involvement. Our internal communication pathways included regularly scheduled conference calls with the principal partners, at varying frequency depending on the stage of the study.

The Community Advisory Committee (CAC) was the primary vehicle for community participation. The members were Community Association Trustee (Chair), environmental health researcher, local physicians associated with the study, one representative from each township in the water district, representative from Ohio EPA, representative from USEPA, County Health Commissioner, and local school system representative. A community project coordinator was employed as a communication enabler. Community advice was particularly sought as to which scientific questions to address, development and wording of questionnaires, communications with residents, and citizen concerns. All CAC meetings were open to the public, and generally between 10 and 30 members of the public attended. The only parties excluded from otherwise open participation in the meetings were officers of the fluoropolymer facility and plaintiff’s lawyers. The rationale was that the community discussions should not be unduly influenced by those with vested interests. The CAC met quarterly and used regular newsletters to keep LHWA district residents, local representatives, and other stakeholders informed on study developments. Newsletters and CAC meeting minutes were posted on a study website.

Study Research Objectives and Methodology

The specific research aims of the study were to:

- determine the PFOA levels in the blood of LHWA district residents and compare these with levels in other populations.
- determine the major sources of exposure (water, air, other) influencing blood PFOA levels.
- determine whether blood PFOA levels are associated with changes in levels of biomarkers of health effects using hematology and blood chemistry tests.
- communicate research results and any recommended exposure reduction interventions to the community, local health care providers, and relevant authorities

Participation was voluntary and the study was conducted with IRB approval. Because of the unusual degree of possible social risk, a Certificate of Confidentiality was obtained, which allows researchers to refuse to disclose identifying information in any civil, criminal administrative, legislative, or other proceeding, at the federal, state, and local levels.³⁰

We measured serum PFOA and certain biomarkers for effects and administered questionnaires to a stratified random sample of LHWA district residents and some additional volunteers.^{8,9}

Development of a Set of General Principles for Communications

The CAC developed a set of general principles or objectives for the communication process at the June 2005 CAC meeting prior to any individual or group results being known to the investigators or subjects. Approximately 20 CAC members and some community members participated in developing the general objectives and principal targets for the communication process. These general principles, listed in Table I, proved very useful to investigators and gave guidance on community priorities throughout the communications process.

Development of Communication Template and Plan

The communication strategy and plan, also developed at the June 2005 CAC meeting, was constructed to be robust for a variety of study outcomes. The principal targets for communication are shown on Table I in the order of priority determined by the community.

The CAC determined that the process required a number of separate, linked, sequential activities, and should reinforce consistent simple messages. Careful timing would be essential so that information vacuums or out of sequence disclosures did not foster the development of inaccurate rumors in a primed community. The communication plan was a “living document” subject to change based on stakeholder input. The plan incorporated objectives for communication at each phase of release of results, target groups, the media to be used, member(s) of the partnership responsible for communication, and content components. The template for these communications is given in Figure I. In addition we sought the advice of selected public relations experts from outside the Southeastern Ohio area.

Principal Research Findings and Recommendations

Median blood PFOA levels for residents were ~80 times those of the general population, and approached levels reported for production workers at the fluoropolymer facility. PFOA levels were higher in children and the elderly. The major exposure source was residential water, with no discernable contribution from air exposure. For residents using only LHWA water, the General Estimating Equation model of best-fit included age, tap water drinks per

day, servings per week of homegrown fruit and vegetables, and carbon filter use. The reduction from use of water filters was much less than from using bottled water. The association with eating homegrown fruits and vegetables could reflect water use in cooking, cleaning, and canning. For LHWA users the blood PFOA was approximately 106 times higher than the PFOA in drinking water. There was no association between PFOA and certain biomarkers of health effects, but this study did not evaluate cancer or developmental endpoints.

Despite not finding short-term health effects, in view of the high serum PFOA levels and potential long-term risks, we considered it prudent to recommend steps to reduce the intake of PFOA from residential water sources. Accordingly our recommendations were:

1. Institute treatment to remove PFOA from Little Hocking system water expeditiously. After installation, monitor continuing efficacy of the removal.
2. Ensure continued reduced emissions of PFOA from the source facility.
3. Consider an alternate drinking water source (e.g., bottled water) if primary residential water source contains PFOA, wherever water may be ingested orally: drinking water, making hot drinks, cooking, making infant formula, and brushing teeth. PFOA does not readily cross human skin, so showering, bathing, and washing were considered unlikely to pose a risk.
4. We do not recommend reliance on a water filter.
5. The West Virginia so-called “safe level” of PFOA of 150 ppb in water may need revision in the light of the PFOA levels found in those who consume contaminated water
6. For issues about personal medical problems and PFOA consult your physician. We will provide information to your physicians on request.
7. We reminded residents that boiling and use of water softeners does not remove PFOA.

Evaluation of the Effectiveness of Communication Plan

To evaluate the effectiveness of our communications we: kept a record of developments connected with the study and of reports in the local media; at each CAC meeting, obtained feedback from CAC members on community attitudes and other relevant information about the community response; and performed a follow-up study between 14 to 16 months after the announcements of results. All participants in the original study were invited to volunteer for the follow-up study. Respondents completed a questionnaire similar to that completed originally [questions included sources of residential drinking water and use of a home water filter]. The date of any change in their residential water source was recorded. Blood PFOA was estimated as described previously.⁸

In addition Mary Hufford, an ethnographer connected with the study, made a qualitative evaluation of community responses and attitudes including at a local agricultural fair approximately two months after the community meeting. An independent perspective was provided in the book by a local journalist.²²

RESULTS

Implementation of Communication Template and Plan

Once the investigators were confident through peer-review that the study results were scientifically valid and robust for dissemination, the communication plan was put into

action. The sequence of communications commenced with mailings to participants at the end of July 2005, culminating in a community meeting on August 15, 2005 where full results were presented.

Notifications to Participants and Authorities—Communication began with a next-day-delivery mailing of results to individual study participants, with the individual's blood PFOA and biomarker levels. Comparative information on PFOA levels was included (see Figure II) and a toll-free telephone number to contact a study physician with any questions. Participants, as well as other community members, were invited to the community meeting where full study findings would be presented. Letters were sent simultaneously to identified authorities and CAC members, to ensure that recipients would be able to respond appropriately to inquiries from the public. These letters included aggregated, but no individual results.

Approximately twenty participants and some non-participants used the toll-free number to clarify issues about PFOA levels, associated illnesses, and follow-up testing; a log was maintained of all questions. Calls often needed to be returned after business hours. Most concerns focused on higher levels in children and the elderly, and possible interactions of elevated PFOA levels and particular medical conditions [Our physicians had previously contacted three participants who had abnormal laboratory values that could indicate health problems]. A "frequently asked questions" list was posted on the study website with appropriate answers. There were no questions from authorities or CAC members. Additional follow-up was required for a few returned letters, mostly due to address changes.

Initial Press Release and Briefing—CAC Members emphasized the importance of engaging the local media. Key local and regional media interested in PFOA were identified and informed of our communication plans by the Community Association around the date the participant letters were sent. An initial press release and briefing were made the second day after the mailing to ensure that participants would have received their letters, but there would not be sufficient time for reporters to interview participants and publish stories in the absence of input from the investigators. Questions resulting from the press release were referred to the PI, but the community association and local health care provider were also available for additional interviews.

Identified media representatives and national news outlets were invited to the news briefing. The release identified that levels in LHWA residents were much higher than those in the general US population, and that water had been identified as the major exposure source. No further details or results were given at that time. Interested parties were urged to attend a community meeting at a local high school auditorium where comprehensive results would be released. The story was reported in local and some national media, the reportage was faithful to the presented results. The CAC felt that the coverage was constructive. Local media representatives were respectful of the strategy to first release information to participants and then to the community. Between the press release and the scheduled community meeting, various interested parties made discreet inquiries as to details of results. All such requests were declined and inquirers politely informed that further information would be released at the community meeting.

Closed Rehearsal of Community Presentation—A strictly closed to the public, full rehearsal presentation was made to CAC members on the night preceding the community meeting, in the high school auditorium. This was the first opportunity for the CAC to know the results of the study. Study recommendations were discussed. CAC members provided feedback on the order of the agenda, comprehensibility of slides, choice of wordings, structure of the presentation, and dealing with likely questions. The presentation was

modified following the rehearsal. All logistics worked satisfactory; no results from the rehearsal appeared to leak to media or other parties.

Community Meeting—Detailed study results were presented at the community meeting, approximately three weeks after the initial participant letter. The CAC requested a presentation that was careful and simple to understand, incorporating a clear visual map so that residents could identify the site of their residences with respect to the study results. The presentation made it clear that this was not the be-all and end-all of studies, but part of a continuum of information.

Approximately 400 people attended the community meeting including representatives of health and environmental agencies, elected representatives including the local congressman, local media (radio, TV, newspapers), representatives of corporations and legal firms, but mostly area residents. “Ground rules” included that lawyers were not to solicit clients, and that questions were to follow the presentation. Representatives from the fluoropolymer facility attended, but were not invited to speak.

The chairperson from the community association introduced the Environmental Justice Partnership and reiterated that there was no funding from any commercial party, and the study was independent of any legal group or lawsuit. Key individuals connected with the study and CAC members were introduced. The study presentation using PowerPoint, lasted approximately 45 minutes, and detailed the aims, methods, results and recommendations. All presentation materials had been carefully prepared to ensure that no individual data was given, and there was no information presented that would allow an individual participant to be identified. The PI indicated that possible cancer risks and effects from PFOA on childhood development observed in experimental animals were not fully addressed by the study and remained of concern. Because of these unresolved concerns residents were advised that it could be prudent to reduce water exposures to PFOA. Almost two hours of questions and answers followed. All questions of a general nature were answered, while questions about individual medical concerns were referred to the toll-free number or answered privately by study physicians. There were very few hostile questions, and those were directed at the perceived polluters rather than study personnel.

A summary describing the study and recommendations, sources of further information, and how to contact a study physician was distributed to all attendees on exit. The presentation and the summary were posted on the study website (over 3000 hits). The summary (see Figure II) and additional information on accessing the free bottled water offer were mailed to all households in the LHWA District, and local authorities and representatives.

Advice from Public Relations Professionals—Public relations experts we consulted from outside the community had concerns with the release of results at a community meeting rather than through the media. Unlike the CAC, they anticipated a hostile audience, advised against a community meeting, and if we insisted on a meeting advised us to have an “exit strategy” and security guards. Consequently we hired a security guard. However events unfolded as the community, rather than the outside experts, predicted.

Results of Communications

We anticipated that some people would adopt the study recommendations and that at the follow-up study approximately 15 months later we would be able to determine the proportion of residents who adopted the study recommendations. We also expected to be able to compare the PFOA levels in those who adopted the recommendations and those who did not, thereby estimating the efficacy of the recommended actions. However after the provision of information to the community, events unfolded in ways that we did not predict.

Provision of Bottled Water—In the mid-afternoon of August 15, with the community meeting scheduled for that evening, fluoropolymer plant representatives announced that, as a result of high blood PFOA levels, up to three liters of bottled water per day per person would be provided free-of-charge to residents of the LHWA district. The LHWA General Manager announced this action at the community meeting. This bottled water was available within a few weeks. As of late 2005, 77.6% of households in the water district had accepted and were receiving bottled water through the LHWA (LHWA, personal communication), compared with 3% bottled water usage by study participants at the time of our study in late 2004. This level of usage continued with little change up to the time in late 2007 when a state-of-the-art filtration system to remove PFOA commenced operation at the LHWA reticulation facility.

Results of Follow-Up Study—244 individuals participated in the follow-up study, 64.4% of the original cohort. The non-respondents included 2 (0.5%) who were deceased, 19 (5%) who were no longer contactable or living in the area, 29 (7.7%) who declined, 77 (20.3%) who did not respond to the invitation and 8 (2.1%) who agreed to be participate but could not be conveniently scheduled.

231 of the follow-up study participants had been drinking residential drinking water known to be contaminated at the time of the initial study. The other 13 had been drinking either bottled water or uncontaminated well-water initially and have been eliminated from the following analysis. The residential drinking water source(s) for these 231 individuals and their residential drinking water source(s) at the time of the follow-up study are displayed in Table II.

Six participants had originally been drinking contaminated well-water, all now used special carbon filters of known effectiveness against PFOA installed by the DuPont in March/April 2006.

Of the 225 previous LHWA water users 197 (87.56%) were now drinking only bottled water, 17 (7.56%) made other changes, and only 11 (4.89%) had made no change to their residential drinking water.

Of the 214 individuals who had previously been drinking PFOA contaminated water, and had made changes, 20 (9.3%) made the change prior to the community meeting in August 2005, 166 (77.6%) had made the change immediately or within 3 months after the community meeting, 9 (4.2%) changed between December 2005 and June 2006, 3 (1.4%) had changed between June and December 2006, 16 (7.5%) had made multiple changes or changed on an unknown date. These results indicate that the change in drinking water source was closely linked to our communications and the resultant availability of bottled water in August 2005.

There was a median reduction in blood PFOA of 26% between the original study in the summer of 2004 and the follow-up study from November 2006 to February 2007.

Qualitative Evaluations of Communications—CAC members reported that the communications had worked as planned. Community members reported that questions had been answered satisfactorily and the availability of the local physicians was appreciated. The community viewed the study as being considerate of the individual, meaning the participants were always informed of results prior to press releases, etc. In general the community looked at this study as one with integrity. The community took notice that this study was not connected with Dupont or any litigation in any way which helped established credibility. Particularly as a result of the availability of bottled water “the edge had been taken off the

issue". These findings were confirmed by Mary Hufford. Later, after the follow-up study and installation of the new water filtration system to remove PFOA, the CAC Chair reported "presently, the water treatment plant is now on-line, and things on the C8 (PFOA) front are pretty quiet. In that respect, provided the filtration system works as planned, the problem has been solved." (CAC, personal communication)

Lyons particularly emphasized the importance to the community of investigator-physician availability and the release of study results locally "which mightily inconvenienced the droves of industry, legal, government and media people who had to travel there for the major announcement".²²

Following presentation to the community, the results were published in a peer-reviewed journal, presented at national scientific meetings, presented at the 2006 USEPA Science Forum (winning first prize), presented to USEPA staff and the Ohio Department of Health Annual Epidemiology Conference. The findings have been utilized to help set drinking water standards in Minnesota and New Jersey, and for a consent decree between USEPA and DuPont. None of these were adversely impacted by the community-first communication sequence.

DISCUSSION

Information released from our study resulted in a series of voluntary behavior changes. We determined that residential water ingestion was the major source for high blood PFOA levels and recommended that residents consider an alternate (bottled) water source. Almost immediately the fluoropolymer facility management acceded to a longstanding request by the water authority to provide bottled water for drinking and related purposes. We believe this illustrates the power of credible information produced and delivered to the community through the CBPR process, to alter the usual power balance within that community. In our opinion, this altered dynamic contributed to the announcement of provision of bottled water immediately prior to the community meeting.

Most community members accepted this offer but others made alternate changes to their residential drinking water sources. We believe that the provision of information led to a "free-market of ideas" both at the fluoropolymer facility and among community residents to address the perceived problem. Some residents chose to lower potential risk by using bottled water, others made different choices: presumably reflecting personal and family trade-offs. Overall a very high proportion of the target population made personal behavior changes to ameliorate the perceived hazard; a far higher proportion than is customarily seen for voluntary public health measures. We attribute this success, at least in part, to the dissemination and credibility of the message coupled with the community's trust of the CBPR research methodology.

Although the results did not provide definitive evidence of harm to humans; with the release of the information that PFOA levels were high, that water was the source and with knowledge that PFOA had potential toxic effects including developmental delays and carcinogenesis in experimental species, each major stakeholder voluntarily acted in accordance with a precautionary principle.³¹ The investigators shared this knowledge and recommended consideration of the use of bottled water. A high proportion of residents made changes to their water supply, both through use of bottled water and in other ways, and the fluoropolymer production facility provided free bottled water to those who requested it. This may represent a natural human tendency for precaution with potential but not yet fully defined hazards. In any case these actions collectively had the effect of mitigating any effect, should one exist, without the burden of proceeding through a potentially contentious

regulatory process. The unique communication model coupled with a precautionary approach voluntarily adopted by major stakeholders generated behavioral changes that were proactive and protective against a perceived, but yet unproven, environmental hazard.

We faced both intense local interest and unique expectations for our research from many disparate stakeholders with varying agendas such as industry, parties to legal suits, regulatory agencies, and environmental activists. There was also a need for medical providers, authorities, and, above all, residents to have credible information. The Environmental Justice Partnership structure, and a defined communication strategy, enabled us to deal with each party in a credible, predefined, respectful and considered manner. At best, a good communication process can empower individuals and the community as a whole. At worst, it can lose the message and destroy scientific integrity. Our plan, and independent funding through NIEHS, enabled us to maintain a communication focus and to emphasize study integrity and independence, rather than be overborne by economic, legal, or media interests. The general principles for communication established by the community in advance provided strong guidance through a complicated set of activities. CBPR programs are shaped by context.³² In this case, the CAC seemed to be more sensitive to local culture and attitudes than outside experts. Some literature on communication of CBPR results devotes considerable attention to negotiating roles and establishing rules for various parties.³² This was not an issue for us. The development of a set of principles to govern communications allowed us to focus on the problems at hand and the need to preserve independence and integrity. The three-partner model of the Environmental Justice Grant program provided a comfortable and complementary set of roles and was empowering for each of us.

For our community the priority order for communications was very important: first participants, then local community, then the broader scientific community, which required some decoupling from the normal “publish and dissemination” sequence. The desirability of Community-first Communication needs to be assessed depending on the circumstances. It may be unwise for complicated studies of complex cancer, developmental or other endpoints, especially if the outcomes are debatable. Straightforward studies of simple endpoints or with large differences in exposure are more appropriate. Similar considerations will pertain to the amount of necessary peer-review. If peer-review by a journal is not practicable, novel approaches to peer review might be applicable, such as convening a panel of outside experts from NIEHS Centers. Finally Community-first Communication is not compatible with the current publication policies of those scientific journals that retain all rights to disseminate the information first. If our success is replicated there may need to be debate as to what extent the needs of science are placed above the preferences and public health needs of a studied community.

Community-first communication supports the underlying ethical principles of autonomy, empowerment, and justice. Autonomy allows for the individual stakeholders to make their own decisions on the basis of deliberation. Furthermore, there is an obligation for various stakeholders to equally respect the autonomy of each other. Keeping promises to the community members allowed them in turn to be able to trust the study team with their confidential medical information. Respect for autonomy is attained by treating others as ends in themselves and never merely as means.³³

Empowerment involves doing things to help patients and clients to be more in control of their own health. Gillon holds that empowerment is the combination of the two moral obligations of beneficence and respect for autonomy.³³ The timely dissemination of individual results and recommendations empowered the community. Individual study

participants benefited from the open communication with the study team and consequently were in a position to make their own healthcare choices and behavioral changes.

Equality is at the heart of justice. Environmental justice for stakeholders in this communication model incorporates fair distribution of scarce resources among stakeholders, respect for people's rights, and respect for morally acceptable laws. The CBPR model recognizes the otherwise disempowered community as an equal stakeholder in the decision making process. Providing meaningful information in a way that fosters the autonomy of the community through mutually respectful relationships is a means to the right to know, the principles of prevention and precaution, and environmental justice.³⁴ The Community-First Communication Model facilitates community autonomy, thereby empowering the achievement of environmental justice.

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Figure I. Community-First Communication Template

The template for the community-first communication model incorporates the objectives for communication at each of phase of release of results, target groups, the media to be used, members of the partnership responsible for communication, and content components.

This information is being provided to help put your blood level of C8 in perspective.

The highest C8 blood levels have been found in workers who were exposed through their occupations in facilities making or using C8. At the --(Production facility)--, the median (middle value of C8 levels in production workers has been around 800 parts per billion (ppb). Occasionally workers have had levels as high as 10,000 ppb. At some other industrial plants, levels have been higher. The highest C8 levels ever recorded in any workers blood have been over 100,000 ppb.

Workers in the non-production areas at the --(Production facility)-- have typically had C8 levels in the 100 to 200 ppb range.

In the general population of the United States the average level of C8 has been around 5 ppb.

Preliminary results from our study have found the following C8 levels in residents in the Little Hocking and surrounding areas (excluding those with significant occupational exposures):

For participants with mailing addresses in Belpre, the median (middle of the group) C8 level was 298 ppb. 50% of the Belpre mailing address residents had C8 levels between 83 and 533.

For participants with mailing addresses in Little Hocking, the median (middle of the group) C8 level was 227 ppb. 50% of the Little Hocking mailing address residents had C8 levels between 187 and 572.

For participants with mailing addresses in Carter, the median (middle of the group) C8 level was 328 ppb. 50% of the Carter mailing address residents had levels between 108 and 477.

For participants with mailing addresses in Vincent, the median (middle of the group) C8 level was 369. 50% of the Vincent mailing address residents had levels between 186 and 564.

For participants with significant additional occupational exposure to C8, the median (middle of the group) C8 level was 774. 50% of this group had levels between 422 and 998.

We are continuing to analyze our results. Further information from our study will be given at the Community Meeting tentatively scheduled for -----.

Figure II. Information Providing Comparative Summary of PFOA (C8) Levels in Blood
This comparative summary of PFOA levels was mailed to individuals participating in the study as well as households in the LHWA District, local authorities, and representatives.

TABLE I

Set of General Principles and Principal Targets (in order of Priority from the Community Perspective) for the Communication of Results

General Principles for Communications:

- Results should be released promptly, but not before the investigators are comfortable in doing so
- Individual participants should receive their results first; to avoid participants first learning study results from the press, neighbors or friends
- The press should be informed in a manner that is both timely and allowed the investigators to control the message as much as possible
- The study must remain a credible source of information
- Communications should maximize constructive responses to the findings
- Communications should minimize pointless concern

Principal Targets:

- Participants
 - The community, i.e., residents of the water district
 - Community Advisory Committee
 - Relevant Authorities and Representatives (County and State Health Departments, State Department of Environment, local water authorities, State and Federal elected government representatives for the area, Local Townships, Sheriff's Departments, US EPA)
 - Local Medical Providers
 - Local Media
 - National media, as necessary
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TABLE II

Residential Drinking Water Source(s) at the Times of the Original and Follow-up Studies (n=231)

Original Source		Follow Up Source	
LHWA	161	Bottled only	138
		LHWA + Carbon-type filter	7
		LHWA+ Bottled	2
		LHWA (unchanged)	6
		Alternate Public water supply	2
		Moved from area	6
LHWA with carbon-type filter	48	Bottled	43
		LHWA with carbon-type filter (unchanged)	5
LHWA + Bottled/spring/well	16	Bottled only	16
Water from Known Contaminated Well	6	Well with specially installed Carbon filter	6