



National Institute of
Environmental Health Sciences



Partnerships for Environmental Public Health Annual Meeting

Reporting Back Research Results

December 13-14, 2018

NIEHS Building 101, Rodbell Auditorium
111 TW Alexander Drive, Research Triangle Park, N.C.

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Introduction

Nearly 150 researchers, public health professionals, and community members gathered at the Partnerships for Environmental Public Health (PEPH) meeting, held December 13 – 14, 2018 at NIEHS. The meeting's focus, Reporting Back Research Results, reflected a critical need to ensure that individuals and communities who are part of research studies have access to their data, as well as information on what those data mean for their health.

A morning of workshops preceded two days of presentations, poster sessions, and thoughtful discussion. Before launching into the first presentation, Liam O'Fallon, PEPH program lead, asked audience members to think about the values that drive them to "report back." "Take 30 seconds and really reflect on why reporting back research results is important to you," he challenged them.

The meeting was organized around the why, who, how, and what of report back: Why is report back important? What are the unique contributions from environmental health science? Who are our partners? How do we report back? What is next for the practice?

Why We Report Back

Although presenters and meeting participants discussed many perspectives on why report back is important, the ethical perspective surfaced as an essential reason to engage in the practice. Across the board, meeting attendees agreed that report back is the right thing to do and that individuals and communities have a right to know their results. On the flip side, participants also have a right not to know their results – to opt out of report back – and researchers need to respect this, as well.

The learning opportunities that report back creates for both study participants and researchers was another commonly cited reason to provide results back to participants. For example, through the report back process, study participants can learn how they are exposed to harmful chemicals and use that information to make personal choices to reduce those exposures. As one presenter put it, "learning leads to action." Researchers also learn from the report back process. For example, several presenters shared how they were able to identify previously unknown sources of exposure by talking with study participants about their results. Report back also helps build relationships with individuals, communities, and other partners, which are critical to the success and sustainability of a research project.

Who Are the Partners?

Presenters shared their perspectives about who should be involved in the report back process and the diverse needs, roles, and expectations of each partner. Individuals, communities, researchers, community engagement cores (CECs), institutional review boards (IRBs), health care professionals, and the media should all be involved. One presenter likened the report back process to a team sport – requiring communication, coordination, and cooperation between all players for success.

Individuals and communities help inform the report back strategy and serve as trusted sources of information for the broader community. Meeting attendees discussed that researchers should work with participants early and often but also be sure to manage their expectations along the way. Participants may expect a study to address their concerns directly or be personally applicable to them. They also may expect researchers to support their advocacy efforts. In order to maintain trust with participants and communities, it was recommended that researchers clearly communicate study objectives, as well as their role after the project is complete.

The role of the researcher includes crafting the report back strategy and framing implications of results for stakeholders. One presenter noted that researchers have a unique set of expectations for the report back process, which often center on the level of interest and effort of the other players. For example, researchers might expect stakeholders to be interested and engaged in the report back process. Additionally, those with access to a CEC might expect them to plan and implement the report back for them.

Meeting attendees agreed that the medical community is a critical partner in the report back process. Pediatric Environmental Health Specialty Units (PEHSUs) were named as a resource to bridge the environmental health and medical communities, with one attendee recommending that researchers “get to know your local PEHSU and involve them early in your projects.”

The medical community can assist the report back process by communicating implications of results to patients and potentially adjusting patient advice based on study findings. To facilitate

What are CECs? Many NIEHS-funded center programs are required to have special team of researchers in their Community Engagement Core (CEC) who translate research findings into information for affected communities, the general public, decision makers, and health care professionals. CECs also help center researchers understand the environmental health issues that are important to their community partners. The following NIEHS-funded programs are required to have CECs: [Environmental Health Sciences Core Centers](#), [Superfund Research Program Centers](#), [NIEHS/EPA Children’s Environmental Health and Disease Prevention Research Centers](#), and [Centers of Excellence on Environmental Health Disparities Research](#).

this mutually beneficial partnership, one presenter advised researchers to provide clinicians with enough information to understand the clinical significance of results so they can answer patient questions and provide guidance. Researchers also should be available for follow-up questions from the medical community.

Another important partner, the Institutional Review Board (IRB), exists to protect study participants. This mandate includes considering the anticipated benefits and harms of report back. Presenters emphasized that an open and collaborative IRB - researcher relationship is key to a smooth review process. “Make friends with your IRB,” one presenter advised.

Presenters encouraged researchers to work with the IRB to develop the report back strategy and to discuss the implications of returned results before submitting a project proposal. This allows the IRB to ask questions and provide researchers with review criteria and protocol templates. Collaboration with Native IRBs is especially important, as they may have culturally-based rules about data ownership, consent, and the publishing or reporting of results.

The media also was highlighted as a valuable partner to help researchers and communities amplify their message and share study results with a wider audience. Presenters emphasized that to maximize the benefit of this partnership, researchers need to present information in a way that is exciting and relevant to the public. As one presenter put it, “you have to find your angle.” Some also warned that when working with the media, it is important to be clear about what the data says (and does not say).

Finally, CECs facilitate communication during the entire report back process. One presenter likened them to “the glue” holding everything together. CECs can train researchers to report back, help craft messages, identify stakeholders, and engage communities. However, to play their roles successfully, CECs need to be included from the start, be provided information about the implications of results, and funded for the time and materials required to plan and implement the report back process. Researchers without access to a CEC can partner with departments/schools of communication at their institutions.

How We Report Back

Meeting participants discussed best practices for individual- and community-level report back, as well as various report back approaches, from traditional fact sheets to high-tech mobile apps. The group consensus was that “whichever method you use, it must meet community needs.”

Other research communities, such as genomics, have been engaged in report back for many years. However, environmental health research has a unique role in the science of report back. Given its focus on collecting environmental exposure data at many levels, as well as individual biological samples, results often have implications beyond the individual, extending to the

community and general public. Consequently, environmental health researchers need to consider multiple report back approaches to best meet the needs of each group.

There are similarities between best practices for individual- and community-level report back, with attendees advocating for in-person meetings to discuss results and implications, including actionable steps, and being available for follow-up questions.

Meeting attendees agreed that at the individual level, researchers should plan for a one-on-one consultation with each study participant to discuss his/her results, how those results compare to the larger population, and health implications. Group or town hall meetings are more appropriate for returning community-level results. It is also important to recognize that the people engaged in the research process may not be representative of the community and that results should be translated for the wider population. As one presenter noted, “it’s just as important to reach the people who are not in the room.”

Meeting attendees also discussed the best way to return results when an exposure does not have a defined level at which regulatory agencies recommend people take action to protect their health. In this case, some advised researchers to work with individuals to help them understand what the science says about potential health risks. It is then up to those individuals to make informed, personal decisions about the level of exposure at which they chose to act.

An important consideration when reporting back at the community level is the fact that harmful exposures often stem from economic or cultural practices that are central to a community’s way of life. Simply put, “exposures cluster around lifestyles.” For example, people living in agricultural areas may be exposed to high levels of pesticides, but the industry also provides the main source of income for those communities. Navigating these nuances requires researchers to understand the local context and to work with the community to find a balance between reducing risk and maintaining the local way of life.

Meeting attendees also shared best practices for creating effective report back materials. They emphasized the importance of including visual elements, such as pictures, graphs, and maps, which can help people comprehend complex environmental health messages. The notion of cultural and community relevance was central to discussions about graphic design. For example, pictures should reflect the target community, and people should see themselves represented in the messages. Color also has cultural significance, especially in Native American communities, and can be used strategically to create materials for a specific audience. However, it is also important to consider color-related accessibility guidelines to ensure everyone can benefit from the message.

When it comes to crafting one’s message, language is key. There was group consensus that results need to be presented in plain language so individuals and communities can understand

results and their health implications. Additionally, materials need to be translated into languages widely spoken in the community.

Messages also need to be actionable, providing people with steps they can take to reduce exposures and improve health, and delivered in multiple formats, from fact sheets to social media. It is also important to include contact information on materials so people know whom to consult if they have follow-up questions.

What's Next?

As the meeting came to a close, attendees reflected on the two days of dialogue and how to build off those discussions to shape what is next in the field of report back.

Many praised NIEHS for its support of report back and encouraged the institute to continue providing direction, leadership, and funding for the practice. Some participants suggested NIEHS add a “report back plan requirement” to funding opportunity announcements to ensure the process is carefully considered before research even begins. Others recommended that NIEHS consider administrative supplements as a means for supporting and encouraging report back efforts.

Meeting participants agreed that engaging the next generation of environmental health researchers will be critical to gaining wider acceptance of report back as an essential part of the research process. They also noted that getting young investigators on board will require incentives and a clear expectation of report back from funding organizations. Training the next generation is also critical. Some suggested adding or encouraging report back to the existing institutional training (T32) programs at some NIEHS-funded academic institutions.

There were several questions about report back in the context of study design. For example, participants discussed when to report results to participants of a longitudinal study, which involves repeated measures over time. In this case, some recommended working with stakeholder advisory boards to understand study participants' expectations. Some cautioned researchers to be careful about returning data before being able to answer research questions, as this may confuse and frustrate participants.

An emerging challenge is how to handle report back when data from multiple study populations is combined to answer research questions. Meeting attendees agreed that the researcher's role in this situation needs to be more clearly defined. “We, here in the room, are the experts and need to begin identifying the opportunities and thinking about how to address these new questions,” one presenter told the group.