

Science Feature: Assessing Health Problems in Local Communities. What you can do?

For years your group has been organized and fighting for cleanup of the waste dump in your community. One of the most pressing questions everyone has had since the fight began is about health effects. Now after a six-year fight, the state has agreed to ask the *Agency for Toxic Substances and Disease Registry* (ATSDR) to do a health study. Initially, you were excited because you thought that someone was finally going to provide some answers about health problems in your community.

Then in the April 1994 issue of *Everyone's Backyard*, you read "ATSDR...Don't Ask...Don't Tell...Don't Pursue" which told of the failures of ATSDR to meet the needs of local communities. Now you're confused and unsure what to do. Is ATSDR going to treat your community like they have every other community? History tells us they will.

Many people in your community are sick and have fought long and hard to get someone to evaluate their health problems. Because they want answers so desperately they may not want to turn ATSDR away. So, you decide to go along with the study. Now, it's not only important to know what to expect from ATSDR, but it's critical to have a plan on how to get the most from them or any health agency or institution who wants to investigate health problems in your community.

One important step is to define "as a community" what you want. Do you want a typical epidemiological study where a questionnaire is distributed throughout the community asking about health problems and the results are then compared to a matched unexposed community? Do you want a clinic set up in the community where people could be tested to evaluate their health? Maybe some portion of the community wants to be relocated or evacuated and you want ATSDR to recommend such action.

Once you're clear on the things you want, then you need to figure out how to achieve these goals. The investigating agency, whether it's ATSDR or someone else, is one of your targets. They are the ones who can give you valuable information and ammunition to help you get what you want. In most cases, they are only coming to your community because of the media, public attention, and pressure your group has already managed to put on the politicians and decision-makers. Be careful not to get totally distracted and let up on that pressure. It's vital to maintain that pressure, even while a study is being conducted in the community.

How can you tell if the investigating agency is friend or foe, or if the study will really help you achieve your goals? You need to ask three fundamental questions, the answers to which will give you a good sense of the intent of the investigators and the limits of the study:

What are the goals of the investigation?

How will the investigators get the information they need?

What are they going to do with the results?

Based on what you find out, you may decide that you don't want to participate in this study. Or you may decide you want to change the agency's plan to something that will be useful to your group. Changing their plan will require a strong organized community effort and a plan to get your points across to the agency.

Involvement and Input at Every Step

The key to influencing the design of a health study is to have input at every step of the investigation, including:

- how the study is designed;
- how the study is actually carried out;
- the evaluation and interpretation of the results;
- the dissemination of the results;
- discussion on what actions need to be taken as a result of the findings of the study.

The most critical of these steps is the first one. If the study is poorly designed, then nothing will come from the study. No amount of after-the-fact analysis can change a poorly designed study. You may need help reviewing the study design and protocols in order to influence the study in a meaningful way. But groups often need money to hire medical or scientific experts to review these health study designs. One demand you can make is for funds to hire your own experts. Anywhere from \$10,000 to review a study design to \$50,000 to participate in all the steps outlined above is reasonable.

Boycotting the Study

One way to change a study is to refuse to participate until you get what you want. By simply saying "no" to the study, you have a great deal of power. Unless the community participates, the agency has no study and will lose credibility if they fail to conduct a study because they didn't meet citizen demands for public participation.

Boycotting a study is not easy to pull off. Just ask the *Concerned Residents of the Yough* (CRY) in Pennsylvania. After years of fighting a hazardous waste treatment and disposal facility, CRY forced the Pennsylvania Department of Health finally to do a health study of the community. CRY asked for and received the study design. With the help of *Center For Health Environment and Justice* (CHEJ), the community quickly found out that the study did not include specific questions about cancer; the number one concern in the community.

After much discussion and debate, CRY members agreed to boycott the study until it was changed to reflect their concerns. At first, the Health Department ignored these residents but found virtually no doors open to them as they went through the community. It wasn't long before the Health Department went back to CRY leadership with a new questionnaire that included the questions they wanted.

A Registry versus a Study

An alternative to the traditional health study is to do a health registry. A health registry is conducted much like a health study. A questionnaire is developed and circulated throughout the community. The data is reviewed to determine the occurrence of health problems in the community and if any disease patterns exist. However, a control population is not needed. Then, changes in these health problems are tracked over time.

The biggest advantage of a registry is in the interpretation of the results. By looking at the rates of health problems in a community, you might find enough information to justify making demands for a clinic, a full scientific study, evacuation or whatever your goals are. At the same time, if you don't find much, you lose little, which contrasts with a full health study where if nothing's found, your community goes to the bottom of the list for action since you "proved" there's no problem at your site.

Before the Study Begins

If someone is going to do a health study in your community, here are guidelines you could use to help assure that the best possible study is conducted:

- The community must be given the opportunity to review the study design and protocols before the study begins (funds will likely be needed to hire someone with expertise to review this work);
- The study must address specific chemical exposures and adverse effects observed in the community;
- Avoid tests where generated results cannot be interpreted;
- The study must have reasonable "power" to detect an effect if present (power is a statistical test that simply defined measures the sensitivity of a study);
- Examples of similar studies where other than uncertain results were found (provided by investigating group);
- Individual medical results must be reported to each individual before being released to the public (if applicable).

In the end, the only way to have a study done that will answer questions regarding health, is to have good experienced scientists do the study. While in theory this is possible, it's often hard to achieve. Many communities where health studies are needed are high profile sites that quickly become

politicized. Bureaucrats and politicians are under a lot of pressure to "do nothing," resulting in studies that are often inconclusive by design.

The best you can do is to make sure that the study design is critically reviewed, up front, by experts working for the community and that the study meets the criteria listed above. This approach should provide an honest assessment of what's going on in the community, even if ATSDR conducts the study. But don't be misled. No single study is likely to answer all of your questions, but a study design that benefits from community input and outside review is a good start. If you or your community would like to know more about how to influence the study design process or need evaluation of studies already conducted, please give CHEJ a call.

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