Community Health Surveys

CHEJ Guidebook P050

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About The Center for Health, Environment & Justice

CHEJ mentors a movement building healthier communities by empowering people to prevent harm caused by chemical and toxic threats. We accomplish our work through programs focusing on different types of environmental health threats. CHEJ also works with communities to empower groups by providing the tools, direction, and encouragement they need to advocate for human health, to prevent harm and to work towards environmental integrity. Following her successful effort to prevent further harm for families living in contaminated Love Canal, Lois Gibbs founded CHEJ in 1981 to continue the journey. To date, CHEJ has assisted over 10,000 groups nationwide. Details on CHEJ's efforts to help families and communities prevent harm can be found at http://www.chej.org.

INTRODUCTION

This guidebook is intended to help you think through the many pros and cons of doing a health survey. It is also intended to help you figure out if doing a health study is right for your community. While it may seem obvious that everyone wants to know if their health has been affected, you would be shocked to know that few health studies have been able to answer people's questions.

This guidebook emphasizes the importance of organizing your neighbors first. It provides steps you can take to establish a strong community group and strategies that may be helpful. We also look at ways to collect and analyze your information and how to use this information strategically in your overall efforts. It is intended for communities who are conducting their own health assessments as opposed to those done by state, federal or local government agencies.

We've collected information on health studies from many different communities nationwide – from Love Canal, New York to Lake Charles, Louisiana to Riverside, California. There have been successes and failures in these communities and we share these experiences so that you can find out what will work best for you.

It's important to put health studies in their proper context. A health survey or registry is simply a tool to help you to understand what is going on in your community. A health study should never be done without knowing how it fits into the overall organizational strategies, goals and objectives to win justice for the victims.

A health study has many far-reaching effects on a community. It can drain your resources, especially financially; it is extremely time consuming, requiring many people and can be physically draining; it can impact pending lawsuits; and eventually, the study can so dominate your activities that it takes on a life of its own dictating what needs to be done and when.

Setting your goals before you undertake this very large and time-consuming task is critically important. If your goal is to prove that your community has been adversely affected by chemical exposures, then you're not likely to succeed. You don't have the scientific credibility to convince the government and the bureaucrats. If you want to use a health assessment to organize your community, this also is not likely to succeed. You need an organized community **before you begin your study.** If you plan on using the information gathered to give you and your neighbors a handle on what's happening or as part of your strategies and tactics you are much likelier to succeed.

COMMUNITY ORGANIZING TOWARDS A HEALTH ASSESSMENT

Community organizing is essential to enable a community not only to successfully evaluate health but to fight for environmental justice. There is little point in trying to conduct a health study or to set up health registry before you begin organizing your community. Fighting a battle to clean up a site that is polluted is a long hard fight. In the fight you will need the support and cooperation of the community to achieve your goals. A community health assessment could be just one of the many tasks you will have to take on. Without a strong community group you are less likely to succeed.

The first practical reason to begin with community organizing, is that people will be reluctant to give you their personal health information without knowing <u>why</u> your are gathering the information. Further, even if people are willing to talk openly and honestly with you about their health problems, it's a giant, time-consuming task to take on a survey or a registry project as an individual. Third, unless you have an organization, what would you do with any information you collected? There are no" magic facts."

Even supposing you, as an individual, overcame the barrier of mistrust and got people to talk to you; even if you overcame the physical barriers of time and expense and came up with a solid, comprehensive report that showed terrible health problems in your community, **So What?** Without an organization to follow through on demands for environmental justice (whether that's compensation or health treatment for the victims or action to stop polluters from polluting), polluting industries and government regulators will simply ignore your findings. They will assume, probably with justification, that there's no community power behind the health report ready to fight for change, and they will just ignore you.

Some people tell us they want to use a health survey to actually organize their community. They'll use the survey to go door-to-door and hope that their neighbors will take an interest in environmental justice issues, due to the simple fact that they have been surveyed. This usually back-fires. WHY? Because you need the participation of 60-80% of the community in order for a health survey to be successful. This level of participation is only possible if the community is already well organized. If you are going to do a study or a registry, then do a study or a registry. If you try to combine a study or registry with "organizing drive," you'll most likely produce a report, which will be easily attacked and dismissed by the policy-makers you intend to impress.

As hard as it may be to accept, public officials are rarely impressed by facts, no matter how compelling or tragic. Woburn (MA) mothers collected information on childhood leukemia in their neighborhood. They documented 20 cases of the disease in their children. They believed the cause of the problem was contaminated drinking water. When they presented this information to their state healthy agency, the response was, "Clusters of disease happen all the time. We don't think this cluster is related to any chemicals in the drinking water." Woburn residents decided to file lawsuits against the polluters and years later, after burying their children, won a sizeable settlement.

At Love Canal, the residents organized a strong community group first and collected the health information later. When it was discovered that 56% of Love Canal children were born with birth defects, residents had a community organization in place. Residents took ACTION to use this health information to press their demands for relocation. Each time they discovered a new pattern of health effects related to toxic exposure, they plugged that information into their organizing strategy. Fortunately, this approach allowed the Love Canal community to win a total federally-financed relocation on October 1, 1980, three years after they started organizing.

In the following sections, the process of how community organizing on toxics problems fits into health issues is discussed. We start at the beginning with the basic steps of organizing. These can be applied to any situation whether you have already begun organizing your community or not, or to a health survey in particular, or if you are wondering where to begin. If you are on the right track, it is always smart to reflect on what you have done. If you're not on the right track, you may find some insights that will give you ways to improve the situation. While reflecting, remember that it is never too late to make a positive change.

IDENTIFYING THE PROBLEM

You think there might be a toxics problem in your community usually people express their first observations as:

1. "We've been seeing (or smelling) strange things." People describe odd run-off from a site, a cloud coming from a suspected polluter, an oil slick, strange odors in the air, bad tastes in their drinking water, etc.

2."There are a lot of illnesses in our community whenever Chemikill Industries is operating." People will describe symptoms experienced by themselves, their children, other family members or even pets or livestock.

3. "We have a cluster of illnesses (or deaths)." People talk about the number of people in their community who have died recently, or who become gravely ill.

These types of concerns often motive people to believe a health study should be conducted. When people see pollutions, they figure, "Gee, if we can prove this is hurting people, we can make the polluter stop, or at least get the regulators to take action." People are emotionally compelled to try to find out why people have died or become ill. Rather than beginning with a health survey, you should begin by identifying the polluting in your community. This is more practical than trying to make a cause-and-effect link between pollution and illness, since even the best health studies do not often make such positive linkages.

You can begin to discover more about local polluting sources by checking at your local planning board, city or town hall, fire department, the county health department and in your local newspaper's library. At the town or county hall (Registrar of Deed Office), for example, you can usually find out who owns the property where you suspect there might be contamination. Sometimes you can tell from the deed how the land was used. The local planning office can tell you what permits, licenses or zoning permits were issued for the property. The local health department might be able to tell you if any complaints were received or citations issued. It is possible that your town or county might even have an official or office specifically responsible for dealing with environmental problems. Your state environmental agency may also provide relevant information from their files.

If you are concerned about plant emissions and discharges, you may want to contact your state or local Emergency Planning Committee. They collect discharge, disposal and storage information from industries, as required under the Community Right- To-Know Law. This law was added to federal Superfund statute in 1986, after people like you lobbied Congress for it.

Your elected representatives at the city, state and federal levels should respond to any inquires. All Senators and Representatives have staff people whose job is to provide "constituent service" which includes helping citizens in their districts find this kind of information. These officials can provide key information, as well as names of other people in relevant agencies you should contact. They also have the telephone number and address of the Right-To-Know Committee chairperson, if you cannot find them yourself.

By contacting these elected officials you can accomplish two important things:

(1) You will often get valuable information, and
(2) You will let them know that you're concerned.

Be specific. Whenever you ask **anyone** to help you, be clear about what you want and establish a "verbal contract" in what you reach a mutual agreement about **when** (two weeks, one month, etc.) you expect action. Following up verbal conversation with a letter saying, *"I'm following up on our phone conversation of [date] where I asked for [what] and you agreed you'd have a response by [when]."* This way, you have a record of the conversation, to remind them of their promise and to make it clear that you're serious.

This is the informal process for acquiring information from government agencies. This process is preferred over the formal process, which is to use either your state's "Open Records" law (nearly every states has one) or the federal "Freedom of Information Act" which applies to U.S. government agencies. It's preferred because the informal approach is usually faster. However, you should not hesitate to use either the state open records law or the federal freedom of information act on any agency that does not respond to your informal requests.

These laws give you very specific rights to information. The federal law, and most of the state laws, define what types of information you are legally entitled to receive, how quickly the agency must respond, and the rules for making you pay for the information (if the agency decides to charge you in order to fulfill your request).

Generally, you can assume you have a legal (if not moral) right to any information, barring trade secrets information that violates confidentiality, or information relating to personnel matters or on-going law enforcement investigations. Most freedom of information/open records laws requires a response within 10 days. The catch is, at least with the federal law, the response" could be as useless as a postcard from the agency that says, "we received your request and we'll get to it when we can." Most of these laws require the agencies to pass along to you all "reasonable" costs finding, copying and mailing the information, but these laws also give the agencies the discretion to "waive" any costs.

Many agencies and non-profit groups can give you a standard, fill-in–the-blanks form letter to implement the Freedom of Information Act. These can be very handy. More easily though, you can exercise your rights with a simple letter that says, *"Dear Mr. or Ms.…: I am requesting under the Freedom of Information Act all correspondence, memorandums, reports, soil, air, and water tests and analysis …"* Be sure to include your name, address and phone number on the letter, so they know where to send the information and who to call if they have any questions.

Once you have collected enough convincing information to show that there really is a problem in the community, **STOP** researching. Leave the remaining research for others who join the group later. Too often, grassroots leaders get so hung up on doing the research that they start saying, *" I don't have enough information yet. I must get more facts before I can talk with my neighbors, before we start organizing and certainly before we start to take action."* Some concerned citizens **never** get past the fact-finding stage and turn into what is affectionately called a "data fanatic." At CHEJ, we have known people who have taken this mania to such an extreme that they have actually had to build additions to their homes to house all the information they've collected. Others walk around---and I'm not making this up---dragging a steamer-trunk on wheels, filled with information.

If you expect to find all the facts before you begin to act, you will never begin to act. When you fight for environmental justice, you need enough information at the beginning to feel secure about your ability to discuss your concerns. As your fight continues and expands, there will be more information to collect including your health survey. You can use this task as a way to build commitment among new recruits who are interested in investigating the problem.

ORGANIZING YOUR COMMUNITY

Organizing a community around a certain issue is not as difficult as you may think. Virtually every community member is affected by the problem. Their health may be at risk, their drinking water poisoned, their property worthless, or their business damaged. Your concerns can also be translated into a tax-payer issue. People get involved in an organization when they see that:

a) they have a self–interest in getting involved and;
b) by getting involved there is hope of addressing that self – interest.

If you are prepared to discuss “pocket–book” issues and “nuisance” problems, as well as health and environmental concerns, you should be able to appeal to everyone’s self–interest, giving them a reason to get involved. It is important to get people involved if you plan on collecting personal health information. As was stated at the beginning of this guidebook, you cannot conduct any type of health evaluations if you don’t have the confidence of the majority of people in the community. People don’t feel comfortable giving personal information to someone they are not sure of and don’t trust.

INITIAL STEPS IN ORGANIZING

The first step to organizing is to educate the community about the problem. There are several ways to accomplish this task:

1. Contact your local newspaper, TV and radio stations to tell the environmental reporter what you have found. Invite the reporters over to your house to show them the documents you have collected. In some company town communities where the polluters own the media, it may not be possible to obtain favorable media coverage. Yet, it is always worth a try because any type of coverage will assist community involvement. There is an old saying that if it’s written in the paper or announced on TV then it must be true!

2. Prepare a fact sheet. When writing this fact sheet remember that you now know more than anyone else in the community. Thus, try not to assume that people already know about the problem. A simple, one page fact sheet will serve the purpose. Information to include might be:

- Your name, address, and telephone number;
- The location of the point of pollution;
- What chemicals people are being exposed to and at what exposure level?
- How the chemicals are getting into the community (air, water, surface contact).
- What types of health effects may result from exposure to these chemicals;
- Who owns or originally contaminated the area of pollution;
- The effects on property values and businesses in this area;

- Additional useful information, such as the nuisance issues of noise, odors, or traffic.

The purpose of a fact sheet is to both educate the community about the problem and tie the problem into the lives of the residents. If community members think they are directly affected, they will be likely to join you your efforts to push for action on the problem. The way to ensure this community involvement is to broadly present the problem, so it applies to everyone. **Not everyone cares about health effects.** People may only care about property values or even nuisance issues.

An interesting way to help people see how they are affected is to also pass out a map with a bulls-eye target on it. You either draw a rough sketch of the neighborhood or obtain a map from the city or county government. The center of bulls-eye is the pollution source. From there, draw circle around the areas thought to be affected by the problem, in reference to health, environmental, property value's and nuisance issues.

Now, you must be wondering how to distribute these fact sheets. You can either distribute them before you go door-to-door, or actually hand them out as you speak with your neighbors. The advantage of distributing them before you go door-to-door is that your neighbors will have already had an opportunity to think about the problem and digest the information you gave them. If you decide to employ this method it is best distribute the fact sheets a week or two before canvassing. As a result, the issues will remain fresh in people's minds and they will be more interested in listening to you. It may be advantageous to mention your canvassing plans in the fact sheet and suggest that they think about questions they may have for you upon your arrival.

DOOR KNOCKING

There is no substitute for door-to-door contact with people. This type of contact is a basic building block of organizing. You can write all the fact sheets you want and call all the elected officials in government, but it is the face-to-face contact that will be your biggest pay off in organizing a strong community organizing. It will also be good experience for you since you'll have to go door-to-door or somehow talk with people later when you begin to collect the health information.

Knocking on strangers' door is always a bit frightening at first, but once you have knocked on a few doors, it becomes easier. Similar thoughts race through everyone's head: Will they slam the door in my face? Will they think that I am crazy or causing trouble? …. and so on. In preparing to go door-to-door, there are several things you need to think about that will make this task easier.

First: Organize what you are going to say. You need to put together a "rap" to use at the door. Successful professionals who canvass for money start their rep with, " I am.." "We are…" "This is…" "We want… your money."

Here's how you can use the same approach.

"I am. …. your name….
"We are…. A small group of parents who are concerned about …
"This is... a fact sheet or petition about the …. problem
"We want you to … attend a small meeting next Tuesday at our local fire hall to discuss our concerns about this problem and what we can do together as a community.

Once you have memorized your "rap," practice it in front of mirror or try it on your family/friends.

As you go door-to-door, people will give you lot information. You will get a good idea of the magnitude of health problems in the community. Name and face recognition by your neighbors will also be accomplished as trust between you and the community begins to build. When you go back to these same people to collect further health information, you will not have to explain who you are and whom you represent.

Second: Bring a notebook to record information gathered during your door knocking. It makes sense to write down all the information your neighbors volunteer to avoid future confusion over who said what.

Third: Before going door knocking, select a date and find place to meet with neighbors who want to discuss the problem. You can create a flyer listing the time and place of a meeting, or simply add the information to your fact sheet.

Fourth: Circulate a petition in your door knocking activities. A lawyer is not needed to write the petition, you just need to write something simple. "*We the undersigned residents of Our Town, USA petition the local/state government body to … do something.."* to test the area or do whatever you want. The purpose of the petition is two-fold: First to get the names and the addresses of people in the community whom you can late contact. Second, to show the powers that be that there are many voting people concerned about this issue.

SETTING UP A COMMUNITY MEETING

So far you have put together a fact sheet and gone door-to-door, put together a fact sheet, and talked with your neighbors. You are ready for the next big step – holding a community meeting.

The first two important things to think about when setting up this meeting is the location and the date. Not many people will attend your meeting if it conflicts with another big event in your town or with the highest rated TV show or during the World Series. Check with others to find out what else happening on the selected date. Choosing a location close to people will bring a larger audience. A neighborhood school, library, church, or community center is the best choice. These institutions are also less likely to charge you for renting the space. If you expect a small number of people to show, the meeting can be held in someone's house or yard.

PREPARING AN AGENDA

In preparing for the meeting, you should think about the following steps:

- At the meeting, have a volunteer sit just outside the door to pass out fact sheets and agendas and and to make sure people sign in on a pad before entering the room. You want to collect a list of names to refer to for future meetings.

- Post the agenda on a large piece of paper at the front of the room. It is also helpful to have other large sheets of paper and markers available for use during the meeting.

The meeting date has arrived, and here you are standing with a few friends in front of 15, 25, or 100 people. Before you bolt from the room with fear, remember these are your friends and want to hear what you have said.

Open the meeting by introduction yourself and others who are working with you. Explain to the group what you are working on and assumption that people know little about the situation, so everyone will be brought up to the same level of understanding and feel comfortable participating at the meeting. Keep your presentation simple and short.

Then open the meeting for general discussion by asking if anyone has any questions or other information to present. General discussion is important to give people a chance to speak and feel part of the meeting. This discussion can go on for as long as it is productive. Be sure to address what people want to do about the problem. Do they want to start an organization? If so, take a vote to establish a group.

It is important to begin the meeting on time. If you begin the meeting late, people will come late. If meetings are long people will hesitate to come back because they may have children and other commitments. You will not be able to fully establish an organization at the first meeting; so do not push to accomplish that task. At the end of the meeting, you might want to go over what you did accomplish. "*We have all discussed the problems and now have a better understanding of the issues. We have decided to establish a group to fight for action on this site. And we have agreed to meet again next* ________. *I really feel good about what we have done this evening.*" This summary will give people a sense of accomplishment and empowerment, and will encourage them to come back.

Since it is impossible to do everything at one meeting, hold several meetings. Important decisions for the newly formed organization to decide include:

- What will the group call itself? A name is important for identification. If you are a group with a name, you are more powerful than an ad hoc group of individuals.

- What are your goals? What do you want? This is probably the most important decision of a group. The goals of the group will determine who joins and who doesn't.

GOAL SETTING

You can initiate the following exercise to help your group in deciding its goals. Use a large sheet of paper at the front of the organization should be.

(1.) You can initiate the following exercise to help your group in deciding its goals. Use a large sheet of paper at the front of the room.

(2.) On a large sheet of paper list suggestions and goals from the people at the meeting.

(3.) Then ask the group to rank these listed goals. What are our top ten goals? Top five? You could end up with 50 goals to sort through including everything from working on the peace movement issue, to getting the community evacuated.

When you chose the top five or ten you'll have your priority goals such as:

Goal #1 - Testing throughout the area.
Goal #2 - Conducting a serious health study.
Goal #3 - Permanently clean up the source of the pollution, etc…

(4.) Next the group needs to decide how to handle these goals. For example, you might decide to begin to push for the first five goals, and as the goals are won, move down the list. The reason behind ranking is to keep the group focused. If goal #29 is to rid the world of caterpillars, you really do not want a committee to spend time studying the caterpillar population.

It's important for everyone to define and mutually agree upon the organizational goals. The beauty of the exercise is that the craziest goal will fall to the bottom without making the person who suggested it feel left out. You will also obtain insight as to what people care about when formulating group activities.

SETTING UP THE ORGANIZATION

Now that you are clear about what you want, you need to establish a working organization in which they feel they have a significant part. Furthermore, you need a good number of people to be involved if you are to collect health information. It takes quite a bit of time and a large number of people to talk with everyone in the community about their health status.

There are three typical formats for structuring a community organization. The most common organization design is the pyramid. This style consists of one person at the top, usually the founder of the group. Under that person are several others (usually 5 to 10 people), who are mainly friends or a "clique" within the group. At the bottom of the pyramid is the community. Generally, the "clique" and leader/founder make all the decisions, do all the work, and complain all the time about how no one else in the community will get involved. Leaders get burnt out pretty fast in this style of organization.

The second type of organization design is consensus group, sometimes referred to as everyone must agree or reach consensus before any action is taken. As a result, these groups take forever to accomplish anything. People generally become very frustrated attending meeting after meeting, with no concrete decisions being made. This group is also the easiest for your opponents to infiltrate and control. All the infiltrator has to do is disagree, and all decision are halted.

The third organizational design requires more energy to enact but is ultimately much more effective. This set up is called the "wheel," and like a round wheel, the skills talents, and interests of your group are addressed. It works very simply. At the center of the wheel is a hub, and from hub comes many different spokes. Each spoke on the wheel on the wheel represents a standing committee. Sample committees include outreach and education, allies, media, research, health information, fund raising, action, etc.

Each committee elects it's own chairperson and co-chair. The committees call their own meetings and decide their course of action. Then all of the committees come together to present their ideas to the entire group.

The chair and co-chair of each committee come to the hub at a set time to explain what they want to do, what they are already doing and the results of their activities. In this way everyone can both share and coordinate the activities of the organization. For example, if the action committee was going to do a protest action, they would need to coordinate that event with the media, allies, and education committees.

The wheel also attracts people because they work on what they think will win, rather than hoping everyone will agree on one specific approach. The "spokes" give people diverse groups to join. If someone only wants to protest, than they can join they action committee. But if someone thinks protesting is a terrible and frightening thing, than they can help with the educational or fund raising activities. At the large group community meetings, the chair of each committee or “spokes” person gives a brief description of what their committee is doing and asks for votes when necessary. S/he also encourages people to join in to help and asks for other ideas.

TARGETS

After goal setting, it is time to identify your targets. Again, making a list helps. There are two key questions to ask of the group:

1. Who is responsible for the situation?

2. Who can give us what we want?

The first question will lead to a list of names of industry polluters and the government agencies who have given them permission or what we refer to as “a permit to pollute.” The second question will establish a list of government officials ranging from the local government to the President of the United States. The two lists can be expected to overlap at times because the responsible party (ies) can also provide the solutions.

The next step in this exercise is to figure out how these people, agencies and corporations are vulnerable. What would make them do what you want them to do? One likely answer for all groups is public opinion. Industry hates bad publicity, and elected officials are concerned about their image with the voters. You can also affect the corporate customers or corporate profits by filing a personal injury suit which will also create a pressure point for the stockholders.

DEFINING YOUR STRATEGIES/TACTICS

There are three strategies commonly used in communities faced with an environmental problem. People usually fight politically, scientifically or legally. Unfortunately, although few communities look at three as complimentary strategies, together they are very powerful. The following summaries outline the values and limitations of each strategy.

LEGAL STRATEGIES’

Community groups who use a legal approach must have plenty of money and time. You must first prove a problem in order to fight legally. You must prove that the chemicals that you are being exposed to have harm you in some way. When you find an attorney who is willing to assist you and file a suit, two things occur. First, you lose members who now believe the lawyer will save the day. The fight has moved from the community to the courts. Second, you stop receiving information and testing from your opponents because of YOUR pending litigation.

Additionally, your opponents may, through "discovery," obtain your health related data as part of the lawsuit. Thus, all those promise you made to your neighbors about total confidentiality become violated.

Investigating routes of exposure (how it got from the dump or plant to you) for your legal case costs several million dollars, as was witnessed in Woburn, MA. Even if you establish a route of exposure, it is nearly impossible to prove that your problems are a direct result of chemical exposures and not by some other exposures.

However, the largest limitation to the legal fight is that it is not illegal to pollute. Industry is actually given permits to pollute by state and federal governments. In the cases where there are no standards for pollution levels, such as residential exposures, the chemicals are seen as innocent and you – guilty of hysteria.

SCIENTIFIC STRATEGIES

Fighting scientifically also has its limitations because there is only a small amount of scientific data useful for your purpose. Very little is known about what happens to people who are exposed to low-level mixtures of chemicals. Scientists have barely scratched the surface on how chemicals harm people.

Fighting scientifically essentially means looking for the "magic fact," the fact that just does not exist. In community after community, people have identified real documented health problems. In San Jose, CA a high rate of birth of birth defects were found among children. In Love Canal, 56% of the children were born with birth defects. Women living in Love Canal also experienced a high rate of childhood cancer. In Texas, there was a cluster of children with brain cancer. None of these terrible findings alone moved the opponents of these communities into doing the right thing.

Communities who fight primarily using scientific facts may suffer from the "dueling experts" syndrome. For example, the community brings in one scientist who will say this community has a problem. Then the government or industry will bring in two other PH.D experts, who will say there is no problem and no cause for alarm. Your community group may become confused because they do not understand the technical arguments or the jargon used. Community people will either doze off during the meeting or stop coming. They have no role and no say since the battle ground is now within the circle of science. The discussions and debates are above their heads and they cannot understand the arguments. If your group falls apart because of this, you will have little power to effect change.

It is quite normal to feel that if you prove there is a health problem in your community, "they" will do something. Although it is normal to feel this way (since we are taught this in high school civic class) it is a bit naive and simply untrue. If a problem is identified, the solution will cost millions of dollars. Neither government, nor industry wants to spend that amount of money to fix it, not without the public demanding action.

If communities are not well organized, they often lose this scientific fight. Their scientists are labeled as biased or liberal radicals, never as conservative mainstream scientists, even when doing conservative work. The governments' or industries' scientists (amusingly) are seen as credible, despite the fact that they are many different disciplines. The arguments you face here are the same arguments the legal system faces when trying to prove cause and effect.

On the other hand, there are several advantages of using science in your fight. First, the information provided by your scientists can give your group credibility. Their studies can show that you are not just making up these horrible stories. Second, the scientific information will give people some information on the types of health problems in the community so they can make decisions. For example, if the results show an increased rate of birth defects, community members may want to do testing during pregnancies to check on development, or pregnant women may want to stay at a relative's home until the problem is resolved.

POLITICAL STRATEGIES

A political strategy means using your constitutional rights through democracy. This strategy involves the most people and uses the general public for the purpose of holding public officials and corporations accountable. The focus is on those who are in office holding elected positions. Proof becomes much less of burden because you are trying to change public opinion rather than proving your case beyond the shadow of doubt. Reaching an elected representative or corporate executive is much more achievable goal then presenting doubt-free scientific evidence. Public officials have local offices or homes somewhere in your state. Political fights also cost less than legal or scientific fights.

History has shown us that evacuating a community, cleaning up a dumpsite, and/or forcing an existing industry to clean up its discharges are political decisions. For example, the first evacuation at Love Canal came as a result of the pressure brought to bear by Love Canal residents while Governor Carey was running for re-election. Love Canal residents followed him everywhere including black tie fundraisers. They carried signs and distributed fact sheets and press statements at all of the Governor's events. Residents held the Governor personally responsible for Love Canal situation.

At Time Beach, MO residents were evacuated when EPA was in big trouble with Rita Lavelle and Ann Gorsuch. Lavelle, head of the federal Superfund program and Gorsuch Administrator of EPA, were about to be thrown out of office, and EPA was being criticized in every news media in the country during the height of these scandals. EPA needed to do something big that would draw a lot of attention and make them "look good to the public". Therefore, EPA approved the evacuation of Times Beach residents.

Political strategies can be supported by legal and scientific information and tactics. For example, you can use the scientific information you have gathered to put pressure on the Governor of the state by saying, "56% of our children have been born with birth defects. How many more will you, Governor, allow to be subjected to these poisons? How many more children must be born deformed before you act to protect them?"

WHAT IS A PLAN OF ACTION?

There are many options open to an organization that wants to apply pressure, educate the public, or relieve tension within a community. However, you must be careful not to overuse or burn out the membership through too many activities. Each action must be carefully calculated, asking such questions as: What do we want to accomplish with this action? Who is our target? Should we take this action now or wait for a better opportunity?

Carefully plan these activities for times when things can be accomplished. If your action is successful, people are likely to come out for the next one. They will feel good about the group and about themselves.

AN ACTION IS USELESS IF NOBODY KNOWS ABOUT IT

Media coverage is critically important for an action to be successful. Be sure to notify the media in advance with news advisory, and have someone make follow-up telephone calls the day of the action. If you use signs at your event, make them large enough so that the cameras can capture the message. Be sure to keep your signs simple and your statements concise. Talk and write in everyday terms that anyone can understand.

There are many techniques for calling attention to your organization or cause. It is beneficial to be creative and develop your own ideas. Some of the actions used across the country are listed below as a base for ideas.

Rally - A Rally is a one-day event for the purpose of bringing attention to your issue, education new people about the problem and motivating people in fight for justice. It serves as a good forum for bringing large numbers of people together, especially if you can use a speaker, entertainment or something else that will attract a crowd. You could use this opportunity to allow the elected officials who support you to speak.

Walk of Concern – Religious leaders or the cub scout can accompany your organization in this walk. You could walk towards an elected official's office, plant gate, or around the site. A news conference and presentation of some sort is helpful.

Symbolic Coffin/Motorcade – You can have an actual funeral march to your target, presenting him/her with a symbolic coffin as a symbol of the death or dying in your community. Motorcading is most effective during rush hour, when you can tie up traffic and make a real statement to a lot of people.

Picketing – This form of protest is practiced by almost ever organization. People carry picket signs outside a designated place. You might want to get a permit for this action although most people don't. Generally, if you keep moving, even if it's in a circle, you will not get in trouble with the law. The advantage of picketing is that it can be used anywhere – City Hall, around the dump, at the president of the corporation. Having fact sheets available for passing cars and pedestrians will generally be helpful.

Prayer Vigil – A church near the site can hold this event. It is good action for seniors and others who physically cannot participate in some of the other activities or feel safer protesting this way.

Talking Outhouse or Dog House – This action will assist in educating the public and obtaining media attention. You need to build an outhouse frame or a dog house. Place a speaker inside the structure and provide someone nearby with a wireless microphone that can be the voice for the house. When people walk by the house, a voice can talk to them about your issue.

For example, the house could say to passerby, *"Did you know governor… is in the dog house? He is allowing the people in OUR TOWN USA to exposed to poisons and die? Although made of nothing more than wood, I am asking you for help. Could you take the flyer from the person behind you, call the governor's office, and ask him/her to help our community? His number is on the flyer."* People actually carry on conversations with these houses. They first think it is candid camera-type show, later they become amused.

Use your imagination when thinking about action. Grassroots groups always seem to have plenty of creativity.

FUND RAISING IS NECESSARY

Part of organizing and maintaining a community group is raising money. You can do lot with little or no money, but you will need to pay the phone bill and printing costs out of the organization's funds at some time. Most people pay for these expenses out of their own pocket during the early development stages, of their group. But soon the pennies add up as will the stress on the family budget. This is unnecessary. If you really have a community organization you should be able to raise enough money to cover your costs.

You must think about the funds you will need to do a health survey and raise the money in advance. How many people pages do your community want to be included in the survey? If you multiply the number of pages by the number of people, you'll find that you will have to pay a certain dollar amount in copying costs. Then you'll need to add other costs associated with such an activity. You will have to raise this money somewhere.

There are many ways to raise money. Here are some ideas on raising money from both inside and outside the community.

$ Pass the hat at your meetings. Churches do this every week and people don't complain.

$ Have a 50/50 drawing. Sell tickets at the door for maybe $1. At the end of meeting, have a drawing. The winner spits the money collected, 50/50 with the organization.

$ Sell T-shirts with the group's name and message on them. The profits on T-shirts are not much, but you can make a profit. More importantly, the design will spread your message. Actions look great when everyone is wearing the same shirt with the same message. It clearly says, "We are together and united in this struggled."

$ Ask local businesses for a donation of money or goods. If a supermarket wants to give your group a side of beef, or an electronic store – a TV, you could raffle that donated gift. Raffles can raise a few thousand dollars for the group.

$ Plan a fund raising dinner/dance. More money can be made when the hall and food are donated. Otherwise, it might be a low profit event, could be great opportunity to give awards or certificates of appreciation to your hardest working people.

Once again, use your imagination when thinking about fundraisers. Talk with other groups in the community and ask them how they raise their funds. It does not take a professional to raise funds for a group. Three ingredients to keep in mind: it should be fun, cost the group as little as possible, and be as simple as possible.

These ideas, learning's, and strategies for organizing a community to take action against hazardous wastes and for protecting public health have proven to work in hundreds of communities across the country. Many of these approaches have also been used by other public interest group to stop unnecessary highway construction improve public transportation, and challenge discriminatory practices. The value of community organizing around any problem or issue should never be overlooked. The power of citizens to organize and directly assert their influence is the ultimate defense for protecting out families, property, and our environment.

HOW TO DO A HEALTH STUDY OR REGISTRY

We have talked about how to organize your community to form an effective group to fight for justice. Now let's look at the actual tasks and issues you need to think about when conducting a health study or setting up health registry.

Collecting health information in a community is not easy. It requires a tremendous amount of time, energy and hard work to be successful. Before beginning, your group should decided if it can afford to give the level of attention that is needed to carry out this type of project. Remember a health study or registry should never be used as an organizing tool. Some leaders may think, "A health study is a great way to build awareness of our issues." While this is true to an extent, there are enough things that could go wrong with a health project, that you should look to better, more tried – and – true techniques mentioned at the beginning of this guidebook.

One of the most critical parts to successful health study or registry is the percentage of cooperation you receive from the community. You must be able to interview the majority of families living in the affected neighborhood. Some scientists have expressed a need for 80% of the population to participate, while others believe that only 60% is necessary. In any case, an unorganized community will probably only yield a 40% to 50% participation rate.

SHOULD YOU CONDUCT A HEALTH STUDY OR REGISTRY?
WHAT IS THE DIFFERENCE?

A Health Study is subject to many hard scientific tests and is generally used for lawsuits and basic research projects. True scientific health studies are conducted scientists. You, a homemaker or layperson, are not qualified to do such a study. If you choose to do a study, you must have a scientifically valid control population, the study must be free from biases, and peer review is necessary for acceptability by the scientific community. In fact, if you are a member of the community, this very fact alone is enough to "bias" the study and invalidate your work in the eyes of scientists and the government. Truthfully, as a local community group you will not be able to do a real scientific health study. More importantly, you do not need to.

Groups that do undertake a health study often fail at meeting hard scientific tests, and the tests will probably come back to haunt you. How? Once an increase of any disease in your neighborhood is identified, your opponent will argue the following. Did you have an epidemiologist look at the questionnaire? Were the statistics done by a statistician? Did you verify all of the diseases with medical records? Did you conduct a study with a control population (all scientific studies have controls.) Were the demographics of the control groups the same as the study group? Did people who had a vested interest in the outcome of the study perform the study? Did you adjust for over-reporting, age, and gender … and so on? The answer to these questions are usually no. Community groups cannot conduct perfect study and opponents will use this against you to discredit you and call your study unprofessional along with any group associated with you.

A health registry, on the other hand does not require all of these hard scientific tests. As a matter of fact, you can point out that you didn't have scientific expertise available to you, and thus your results are probably an **underestimate** of the real problems.

A health registry is conducted the same way as a health study. You circulate a questionnaire and review the data to determine if any disease patterns exist. But you do not need a control population, although you can still use one if you like. A registry can be an on-going activity of the group. With a study, you look at a certain period of time, and than stop. With registry, you can continue to keep a record of changes in the health of the people who live in your neighborhood.

The most significant advantage of a registry over a study is in the interpretation of results. If no increase in disease is found with a registry, you will not endanger the credibility of your group. You won't be hurt by that result. If you did a study and found no increased health problem, your group could look very foolish. Your opponents will be the first to jump on you, to verify the claims they have made about your organization. And, they will accuse you of falsely creating hysteria in the community.

This situation has actually happens in several communities and it literally tore the groups apart. In one community, their site was even put at the bottom of a list for immediate action since "they proved themselves" that there was no problem.

Remember that the purpose of a registry is to monitor community health to see what happens over a period of time. This monitoring device may not show an immediate increase in disease, but as an on-going project, results may change. In certain diseases such as cancer, for example, you cannot expect to see an increase for 10 to 20 years after expose.

If this health registry information indicates serious problems, you could demand that certain steps be taken by the responsible agencies or polluter. For example, you could explain that you found a high level of childhood cancer and you want … (what ever your goals are). You could even take it a step further to say you want a full scientific health study done in your community. Arguing that although you identified this result, it is probably an underestimate of the true problems, after all you're not scientists.

BEFORE YOU BEGIN

Once you have thought through the questions of time and people power, there are several other questions to ask before undertaking a study or registry. The following questions were derived from both the good and bad experiences of other community groups faced with gathering health information. You can avoid their mistakes if you think through these questions. Answering these questions will help you define what you want to do and how you want to do it.

1. Why do you want to do a health survey or registry?

Do you think there is an increase of a certain disease in the neighborhood? Do you want to find out about the neighborhood 's health status? Have several of your neighbors reported similar health problems to your organization? Do you want to prove that you're not crazy like all your opponents accuse you to be?

2. What do you hope to accomplish in conducting a survey?

Do you want to convince your neighbors or your elected officials that there is a problem? Are you planning to use the result (if positive) to pressure the health authorities to conduct a detailed scientific study? Do you want to use the results to put pressure on the "powers that be" to evacuate or clean up the point of pollution? Does your attorney plan to use the information in a lawsuit?

It is important to define your major goals in advance in order to determine if a health survey/registry is appropriate for your situation. If appropriate, you decide, step-by-step, the best ways to achieve these goals. Do you want to do a health study or health registry? There is a big difference between the two, and based on your goals, one may work better than the other.

THE SIZE OF THE COMMUNITY IS IMPORTANT

The next step is to ask yourselves if your community is large enough for either a study or a registry? If the community is really small it may not be worth your while to invest the time and resources in doing a health survey.

Size is important because there are a certain number of diseases expected in every population. A health survey must have a high enough number of participants to show that your results are valid. In other words, you must prove a disease is higher than normal or higher than the expected rate of that disease and higher than just by chance alone. For example, if you would normally find that one out of every four people in any community has cancer, and then in your population of 1,000 people you would expect 250 cases of cancer (1,000 – 4 = 250). If the numbers of cancers exceed that amount, say 300 cases, then you have a significant number of cases.

When surveying a smaller population such as 20 families consisting of 80 people in total, you would normally expect to find 20 cases of cancer (80 – 4). If there are 20 cases or less, you cannot show an increase in cancer in your community. If there were 16 cases of cancer in your community and one case occurred in each family, you could argue that 16 out of 20 families (80% of the population) have the disease. Thus, given 80% of the families have cancer, a problem must exist. Although these facts may be literally true, they are not accurate or honest assessments. The number of disease cases must be compared with the number of the total population, in this case 80, not the number of families. So, 16 cancer cases in 20 families (80 people) actually means 20% of the population is affected, which is less than "normal".

WHAT IF THE HEALTH SURVEY SHOWS AN EFFECT?

The situation created by a positive outcome of the health survey must be treated properly. People in the community will be full of fear, anxiety, and emotional problems that cannot be ignored. Families living in the area are going to want to know what they should do to protect their families. Questions will surface which need response, such as: Should I leave everything I've worked for all my life and move out to protect my family? We have waited five years to have a baby; do we put it off even longer? We are not getting any younger – will the unborn child that I'm carrying be o.k?

Not all people are as strong are as we would like to believe. So once you have taken the impact of the repercussions of the survey results into consideration, you must provide some mechanism to assist the concerned residents. Your group might think about bringing in a supportive family doctor to answer questions or give advice on preventive tests people might want to include in their yearly check ups. You might want to arrange to have the local crisis center establish a "hot line" for your community. Or you could establish a support center within your own organization.

LEGAL ISSUES INVOLVED IN HEALTH SURVEYS

There are two major legal issues to resolve before you start: the statue of limitation laws defines a specific period of time during which a person who has suffered can file a lawsuit to recover damages. In most states, the laws say that within "x" number of years following discovery of your injury, you must file suit against whomever caused that injury. In some states, the period allowed is as short as one year.

Your survey could cause the statute of limitations clock to start ticking. By causing people to “discover” their injury through your survey, you bear some responsibility for helping people protect their legal rights.

If you act responsibility, this provision is not a problem. Find out from a friendly lawyer, your local legal aide or the Bar Association what your Statute of Limitations laws are and how they might apply to the situation in your community. Inform people of all their legal rights, especially if your survey indeed starts the clock. You may want to suggest that people who “discover injury” through your survey contact a lawyer. You could set up a referral plan, but keep in mind that this creates even more responsibility, as you would need to vouch for the lawyers you refer people to.

This issue of privacy through discovery has far reaching effects. Your opponents, the responsible parties, could ask the court to order that you give them all of the health information and identification document you have collected. If this happens, you would be providing the other side with everything you know about peoples’ personal health problems and histories. The opponents will use all of that information to build their case against your neighbors, and you will have broken your promise of maintaining confidentiality to the community. Even though it is not your fault, people will feel violated and angered. The next time you make them promises, they will doubt your integrity.

At Love Canal, Occidental Petroleum tried desperately to obtain such information from the Love Canal Homeowners Association. They never succeeded but they got close. At the Stringfellow Acid Pits in Riverdale, California, the opponents were successful in obtaining this health information. In this case, the potential responsible parties actually got the California State Department of Health’s surveys results and related documents. This was a state sponsored study not a community-based study, but a community’s study is subject to the same legal arguments.

One way you can protect the confidentiality you promised the community is by removing names from the questionnaires and then destroying the identifying master page. This entire problem can be avoided by not doing a health survey at all. But the point is not to discourage you; it is just to make you think about the privacy and discovery issues. Then, your lawyers will have no surprises to present in court nor will your opponent need to ask very many questions.

A health survey or registry is a tool to help you understand what is going on in your community. It is an element of your strategy to win justice for the victims. The results can be far reaching in affecting the families themselves, lawsuits, and overall goals of the group. Such studies require many people and resources to the point of physically draining the group.

Health surveys cannot be taken lightly. You must think through the various questions raised in this section and furthermore, think of other questions on your own. If your organization chooses to undertake such a project, step carefully through the maze.

Think through each step – where your group will go and how it plans to get there. Look carefully at the problems and obstacles and how they can be overcome. Adequate planning and foresight could make such surveys extremely advantageous.

CONDUCTING A HEALTH SURVEY

To identify the "exposed" population, you should begin with an area map. You can obtain one (two is even better) from your tax office, city hall, or possibly the county building. Once you have the map, mark the homes (if not already indicated), the dumpsite creeks, rivers, surface water, or other waterways. Indicate which way the water flows. Use pencils in case your need to move your drawings. Think of what else could carry contaminants. Which way does the wind usually blow? Are there swampy areas where water pools after a heavy rainfall? You should be looking for "pathways," where the chemicals travel from the landfill or source of pollution to nearby people.

Call some of the older, long-time residents who have lived in the community for years. What can they add to your map? What was surrounding the site before the homes were built? Were farmers' field tiles laid beneath the surface? You can add more details by studying a United States geological survey map, or talking with a hydro geologist that knows the area (check at your local college or university). Different items placed on the map should be drawn in different colors – Can you quickly distinguish a creek? Can you easily locate the more contaminated areas? Which homes are closest to the site? Which homes receive the direct winds off the site?

Now that this map shows an idea of how far and where the contamination might be found, you should plot the areas (air water and soils) that might have been tested by government industry. Do higher levels match where you expected them to be? If not, don't worry. Government agencies' tests have often been proven inaccurate. Yet you may not know something about the movement of wastes from the site and, therefore, should check out why your maps and their results are different before dismissing them.

Don't forget to include the source of your drinking water on your map. Answer the following: "Where does your drinking water come from?" Is everyone on town/city supply or does each family have their own well? Are several families on the same well water supply? How deep are the wells? How old are they?

Now you are ready to define the highest and lowest exposed population. Your study can be used for several purposes, so you must decide how you can "key" the questionnaire accordingly. Here are the various ways to look at the community:

1. Define the outer boundaries of the affected community. Where do you think the people are exposed and where are you pretty sure they are not?

2. Once the outer boundaries are defined, you can further break down the community by determining who may be receiving the highest level of exposures.

Blocks 9, 10,11,12, and 13 have moderate exposure. Blocks 2,3,4, and 5 have the lowest exposure.

For example, people living on blocks 1, 6, 7, and 8 of our sample map are probably receiving the highest exposures. Blocks 9, 10, 11, 12, and 13 have moderate exposure. Blocks 2, 3, 4, and 5 have the lowest exposure.

This community "exposure" breakdown can be used to compare the groups individually (i.e. the highest exposed to the other two areas, the highest to the lowest, the moderate to the high and low, or any combination).

By making several different comparisons, including comparing an exposed to an unexposed population outside of your periphery, you will get a clear picture of the health of the health problems occurring in your community. These comparisons may also remove some of the biases (or questions) of an over reporting population.

DATA ANALYSIS

Once you have defined the exposed and unexposed population, you have one more step to think about before you are ready to conduct your interviews: What will you do with all of the data you collect? How will you analyze it and make any sense out of it all.? You need to think about this before you conduct your first interview so that the questionnaire is properly marked.

There are several ways to analyze the data: by hand, computer, or to take it to someone else to do – someone at a local college or university. If you have someone who is good on a computer, maybe he or she can put together a program that will fit your needs. Even so, you are going to need someone to enter all of the information into the computer. If you chose to do it by hand it can be a very long and tedious task.

If you find someone at a local college or university who is willing to help, then you should be careful about who owns and controls the data and the release of the data. You need to be clear about the time it will take to process and you may want to check to be sure the school is not support by the polluter through contributions or Board membership.

HOW TO BEGIN TO CONDUCT YOUR SURVEY

Step 1: Define who will do your survey.

The ideal situation is to identify an outside party to interview your community such as a church group, graduate or undergraduate students, United Way, or another community organization. Having an outside group will reduce the "conflict of interest" concern the authorities always use when a survey is conducted by the community itself (especially if an adverse health effect is found). Unfortunately, the ideal situation is rarely possible. Alternatively, identify a <u>small</u> group of volunteers in your community who would be willing to assist you.

Choose your assistants carefully. If an individual is known to gossip, **do not let him/her help!** Confidentiality is vital to making the survey a success! One slip of the tongue could – and will alienate the whole community. Include people who will keep their commitments to the survey and who are dependable to do the work they promised.

Step 2: Define how you to conduct the interviews.

The two primary ways to conduct the interviews are over the telephone or by going door-to door. Here are the pros and cons of each method.

The telephone survey is the easiest way but not the best way to conduct interviews. People tend to be suspicious when someone calls and asks personal questions about their health and lifestyle.

How are they to know for sure that you are who you are? The caller might be perceived by the resident as someone working for the industry responsible for the contamination. Generally, people do not take the time to think when answering questions over the telephone because they do not want to be bothered, or are not interested. If they quickly hang up, you will never get the chance to explain to them the crucial importance of the health survey to the community.

The best way to conduct the interviews is by going door-to-door. This way, you will at least have an opportunity to speak to individuals face-to-face to convince them that the survey is necessary. You will also have the opportunity to sit with the residents and take the time to carefully fill out the questionnaire. Since the questionnaire is rather long, the resident will not have a tendency to rush through it or cut you off, as they might over the phone.

A week before interviewing, you should send out a flyer announcing that the health survey will be conducted. This flyer should include how you will be conducting the interviews (telephone or door-to-door), when you will begin, who (individual names) will be assisting with the survey, why the survey is necessary, the area which will be included (one block or one mile,) and a contact number in case of questions. This will help residents to understand and feel better about speaking with a stranger about their health. Residents can then ask for the name of the person knocking on their door or their identification, and check it against the list.

In addition, you should let people know that special arrangements will be made for the disabled people and others who are unwilling or unable to answer the door. (You might want to notify the police department prior to going door-to door in case a concerned neighbor thinks you are doing something wrong and calls the local police department. The police can reassure that person that you are legitimate.)

Step 3: Train your interviewers.

1. Set up two or more meetings with everyone that will be working on the health survey. All workers need to be trained in the same manner to ensure that all residents are interviewed in the same way. Lack of consistency is a recurring complaint of the health authorities will also point out that the community interviewers are looking specifically for one or two diseases and, thus, are not objective. Train your interviewers to avoid placing too much emphasis on common diseases during their questioning.

2. Provide each interviewer with a composition notebook. This type of notebook will remove the temptation to tear out sheets of paper. They should carry it to all interviews and meetings to record note of explanations, questions, and people's stories.

3. Explain and emphasize the need for confidentiality! No one should ever report a name or health problem that a family has voluntarily submitted to him or her in a questionnaire. Interviewers should not talk among themselves or to others outside the group about information they have gathered. Residents will not participate if they believe that there is a chance that their given information will "get out". If the interviewer is asked by the resident what health problems he/she has found, the reply should be, "I just don't know until the surveys are all in and counted. As I promised you, due to confidentiality and to protect everyone's privacy I cannot discuss anything I hear."

4. Be sure interviewers read the questionnaire and understand all the words and terms used. They should know what every word means! If there is a disease or term that nobody has heard of, you should call your local physician or hospital for a definition. Remember, in order to avoid another one of those never ending accusations of bias, do not let the interviewer show the questionnaire to **anyone** in the community before you begin. The only people in the community that should see the questionnaire before the actual interview are the people conducting the survey.

Step 4: Learn how to fill out the questionnaire.

It is essential to teach your interviewers how to fill out the questionnaire. Be sure to do the following:

1. During one or more of your interviewers' meeting, go through the questionnaire line-by-line, question-by-question, until everyone thoroughly understands each question. Practice different role-plays on your fellow interviewers, playing devil's advocate and asking them silly pointed questions. Then you and your interviewers will completely understand the questionnaire before approaching the community.

2. The questionnaires should all be pre-numbered so a duplicate number <u>never</u> appears. Therefore, after photocopying the questionnaires, one or two people should number each one in the space marked ID # ______, as appears on the cover page and on page two. The numbers must be the same! During the interview, page one should be filled out with the necessary information, then torn off and placed in a designated large, brown envelope. Be sure (take the time to check) that the page with the resident's name and address on it is place in the brown envelope before asking the health questions. The resident will feel a little more comfortable about giving you personal information. Once you put the cover page away, you can convince convince them of their anonymity – they are only a number. However, it is usually the trust invested in the person doing the interview, rather than this visible procedure, that convinces the interviewees of confidentiality. Your interviews must be capable of building this trust.

3. The questionnaire itself must be easy to follow and fill out. All the questions need a place for an answer to be either checked or written in.

4. Ask each question the way it is written. Even if you know the persons has asthma, or he/she has already stated that he/she has had a medical a problem, ask it again when you come to it. Then you know that all interviews are conducted the same way, and therefore, are consistent.

5. If the resident cannot answer a question, or is doubtful about their answer, mark it as such. Do not leave any questions unmarked because this may be interpreted as the interviewer forgetting to ask or mark the question. If the resident said he/she will look up the information and get back to you, mark down the number (ID#) to give to the resident for reference when he/she contacts you later. You might also want to make a note to yourself (use their number only) just in case they lose their number.

6. If the resident does not know the disease you refer to, than they probably do not have it. If the resident wants to know what the disease is, you can tell them, but still mark a "no" response.

7. Carry a few extra sheets of paper with you at all times (the paper should be the same size as the questionnaire). Then you will have extra space if there is no more room on the questionnaire. When using the extra paper you should include: ID #, page

number, section of the questionnaire, and the number of the question F. Then it can be traced back to the master questionnaire if it becomes separated.

INTERVIEWERS' APPROACH

You must approach a family very cautiously! Remember you are asking them for their most personal information. Begin by introducing yourself, then explain exactly what you are doing, the reasons why you are conducting the survey, and the group you represent. For example:

> "*My name is ___________ and I am working with the ______________________ organization to conduct a health survey on the families who live in this neighborhood. Maybe you have heard about what we are doing from the article we ran in local newspaper or through the flyer we distributed last week. We are conducting this survey to determine whether or not there is an increased health problem in your neighborhood. The survey is designed to protect all information and maintain this information in the strictest confidence. No one will ever know your personal information because your name is removed before we even ask the first health related question."*

If the family readily cooperates – **Great!** You can make a little small talk before you begin, which will make the family relax and build confidence in you.

However, if a person becomes hostile or defensive saying, "there is no problem here! Why don't you go back home and behave yourself, stop causing trouble." - DO NOT become angry or defensive! Instead, calmly explain that this health survey is the perfect tool to prove that he/she (the hostile person) is correct.

"If we conduct the survey and nothing shows up, you're right, and we will go home and stop worrying. But, in order to prove you are right, we need everyone's cooperation, including yours." If the person is still hostile and refuses to participate, do not hit him/her! Just politely thank them for their time and go on your way. (Better known as "kill them with kindness"). Never become angry, or argue with a person like this, or you may alienate them forever. In most communities there are groups of people who regularly speak with one another and if you upset one person in that little circle, you could end up losing everybody in that group.

WHAT TO DO WITH ADDITIONAL INFORMATION

In your door-to-door survey, you will be speaking with many families who have additional information to offer. Information such as: ‘I saw Company X dump here.” There is a black gunk on the walls of my basement.” “My trees are dying,” or “The previous owner had the same diseases I do.” This information must be striking down because you will never remember who said what and you may need the information at a later date. The composition notebook comes in handy here. Write everything down in the book, with the resident’s name and the date. You can use the name, as the information is not confidential health data. These facts can provide essential reference material and will make the resident feel worthy. You are paying attention to what he/she are saying, making the resident feel that he/she has contributed to the investigations. Remember to record all information even if it seems irrelevant. It is careful data gathering that will lead you and your group to successfully achieving the goals you established in the beginning.

The next section is the questionnaires. There are two questionnaires, one for children, and one for adults. The questionnaires are long and ask many questions. You may want to use them in full or pull from them the questions, which are reflective of your community’s health concerns. For example, if you have a primarily high population of seniors you may not want to bother with the questions on reproductive histories. Or if you have a very young community you may want to make reproductive histories the primary focus or your survey.

Use your judgment or call CHEJ for help if you need to identify questions that make sense. Please remember the longer the questionnaire the more analysis that needs to be done. This could take months for a long survey.

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