ANNALS OF FAMILY MEDICINE

Online Supplementary Material

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Supplemental Appendix. Interview Guide

When we talk about health research, it means many things to many people.

We're interested in what you all think about health or medical research?

What are the good things and the bad things about health or medical research?

Do you know anyone who has had personal experience with such research?

The types of projects that RIOS Net does are different from lots of other health research. For instance, instead of testing different drugs to see which is better, RIOS Net projects look at health problems and how doctors treat them to see what works best. Let me give you an example of what I mean.

One project that RIOS Net is doing will help doctors learn more about a type of skin condition that may mean someone is going to get diabetes later on. If this is right, a person who has the skin condition can do some things to help avoid getting diabetes. Knowing if this is true would help doctors give better care to patients. To learn about this skin condition and diabetes, RIOS Net doctors need to write down some information about the patients they see. Here is the paper they use to write down that information:

(Distribute copy of modified data collection sheet. Review elements. Point out that no identifying information is on the sheet).

This study is an example of health research that uses information about a patient, without actually doing anything to that patient. ***What do you think about this type of health research that just uses information about patients, but doesn't do anything to patients?***

POTENTIAL PROMPTS TO ELICIT MORE INFORMATION

- What do you think are the good things **people** might get out of this type of research?
- What do you think are the good things **communities** might get out of this type of research?
- What do you think are the bad things that could happen to **people** because of this type of research?
- What do you think are the bad things that could happen to a **community** because of this type of research?
- How can people be harmed by being part of this type of research?
- How can people benefit by being part of this type of research?
- Would it be good or bad for (this community) to be part of this research?
- Would you personally be willing to have this information written down about you if you came in to see your doctor when s/he was working on this project? Why?

We all worry about our own private health information getting to someone who doesn't have any business knowing it. In the project that I just described, the doctors don't write down anything that could give away the identity of who they are seeing, like the patient's name or address. But what if the doctors did write down the patient's name? ***What kinds of things would you worry about happening to you if someone got the information who should not have it?***

Is there anything special about (Navajo/Pueblo/Hispanic/rural) communities that would make it especially bad for private health information to get to someone who shouldn't have it?

POTENTIAL PROMPTS TO ELICIT MORE INFORMATION

- Are there things that you think medical people who do research like this should know about the dangers of private health information getting to someone who shouldn't have it?
- What would people in this community be most worried about if they knew their private health information was getting to someone who shouldn't have it?
- Is there anything that can happen to communities, not just the person, if private health information gets to people who shouldn't have it?

Right now, anytime doctors want to do health studies, they must get approval first from special committees at hospitals. These committees think about the good and bad things that might come from the research; they also make sure that researchers protect the rights and safety of patients who participate. Usually, the doctor doing the research has a paper that tells any patient participating in the research all about the study. The person must sign this paper if they agree to be part of the study. In some studies, the person doesn't have to sign the paper, and doesn't even have to be told about the research. In other words, a doctor could collect information about a person and use it for research without that person even knowing about it. Let me give you an example. Suppose doctors want to find out if people with diabetes are getting treatment they should be to prevent kidney problems. The doctors might look at the medical charts of diabetics to see what kind of treatment these patients are getting. ***What do you think about this kind of research where doctors look at records without getting the patient's OK? Is it all right if it is for a good purpose?***

POTENTIAL PROMPTS TO ELICIT MORE INFORMATION

- Is there anything that could still happen to a person if health information about them, even if you can't tell it is about THEM, were to go somewhere else besides the research study?

Let me ask about another situation. Suppose a doctor wants to do research to find out whether people with pneumonia are being cared for in the best way possible, or maybe research to find out whether people who've had heart attacks are getting needed exercise. The committee decides that the doctor's research project is a good study. The doctor now needs to find people who've had pneumonia or heart attacks to see if they want to take part in the research. ***Is it OK for someone working on the research to look at patients' medical charts to find the names of people who've had pneumonia or heart attacks so they can then contact these people to see if they want to be part of the research?***

POTENTIAL PROMPTS TO ELICIT MORE INFORMATION

- Would it make a difference if the study might find something that would help people with pneumonia (or heart attacks) a lot compared with if it might find something that would help only just a little?
- Would it make a difference if the person looking through the charts or lists was someone who works at the clinic compared with someone from outside who is doing the research?

I'd like to ask about something else, now. There are probably some types of health conditions or health information that people especially want to keep private. ***What would you say are some health conditions that people want to keep especially private***?

POTENTIAL PROMPTS TO ELICIT MORE INFORMATION

- Why would people want to keep [identify condition(s) mentioned by respondents] especially private?
- Are there any health conditions or health information that it's okay for people to know about?
- (Explore expected situations—HIV, STDs, etc. Check on genetic conditions, infectious diseases (eg, TB), any other conditions that label a person as undesirable?)
- Have any of you ever heard of any examples from around here where someone's private health information was told to someone who shouldn't have known about it?
- Did anything happen to the person whose private health information it was?

Like we said before, people all over the country are worried about the problems that might happen if their personal health information isn't kept private. Because of this, the government is making new rules to protect people's privacy about their health information. The government is also trying to make sure that important health research can still go on. For example, one of the new rules says that if a health research project is a good one, the researchers can use some information about a person for a study without the person knowing about it, as long as the researchers don't have the person's name, street address, social security number, or telephone number. ***What do you think about this rule, which allows some research to go on without a person's permission as long as it doesn't include information that says exactly who the person is?***

POTENTIAL PROMPT TO ELICIT MORE INFORMATION

- (Example: Research like this may allow a researcher to mark all the cases of premature births in a county, using the neighborhood of where the mothers live, to figure out if there is an area where there are a lot of premature births so a program can work in that area to reduce the premature births)

- In a research project that uses this kind of information—that doesn't say exactly who a person is, but might include some information that would make it possible to figure out who a person is—is it possible that some kind of harm could come to person?

These are all the questions that we wanted to ask, but before we finish, I want to ask if anyone has anything else they want to say about the things we've been talking about today.

We are going to pass to each of you a sheet of paper now. If anyone thinks of something else they would like to tell us about what we discussed today, you can write it down on this, and either give it back to us now, or mail it to us with the envelope.

I want to remind everyone that we'd like to keep what people said here today private, and that no one should talk about what anyone said here. We'll be asking other groups of people from around New Mexico these same questions over the next 6 to 8 months. Afterwards, we'll put together a list of what people told us about what is important to keep in mind about private health information. This list will be important for RIOS Net, but we will also share it with other health researchers who need to know about these important issues. Before we are done with the list, though, we would like to share it with you. If you would like to look it over, and make any comments on it you will be able to. Since we won't have your names or addresses, we can't send it to you, so we will leave a copy at the [insert community name] office. We hope to have it there during next [insert timeframe].

Now that we are done, I want to again thank you very much for spending the time to talk with us today.