

Unit 2: Written Training

Unit 2: History of Scientific Research with People and Rules

Topic 2.1 Unit: History of Scientific Research with People and Rules

Now that you know more about what research with people can look like, you need to also learn about how to treat people well in research and keep them safe. First, let's talk about the history of research with people.



We already talked about some of the really good things that can happen when you do research. It is also important to talk about **harms or risks**. Harm or risks are some of the bad things that can happen in research.

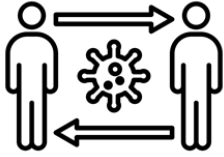
Sometimes we know bad things might happen, but they won't happen often or hurt people really badly.

Sometimes we are surprised at the bad things that happen. Sometimes we can stop bad things from happening. Learning how to stop bad things from happening is one of the reasons you are doing this training.

Unfortunately, there have been times when researchers have hurt people. We now have rules so that people in research will be treated well. We'll get back to that, but first, let's talk about two examples of researchers hurting people many years ago.



One happened at an institution for kids with disabilities in the 1950's—Willowbrook in New York. Back then, most people thought it was a good idea to have people with disabilities live in institutions. At Willowbrook, the researchers gave the kids a virus that could make them sick. The researchers sometimes told family members that their kid could only live at the institution if they were in the research study. The researchers didn't think it was bad to make the kids sick because they would probably get sick anyway living in an institution.



Another example of people getting hurt in research happened in Alabama starting in the 1930's. The researchers were interested in learning about a sexually transmitted infection called syphilis. The researchers didn't ask the Black men if they wanted to be in the study, lied to them about parts of the research, and offered them things they really needed, like food and medical insurance, so it was hard for them to say no.



While the study was still going on, we learned about a treatment for syphilis, but the researchers didn't give it to the Black men or tell them about it because they wanted to keep doing research about syphilis.

People agree that the things these researchers did were not right. So bad things like this don't happen again, we now have rules to help make sure people are treated well when they are in research. These rules are all about ethics.



Ethics is about making sure we take care of people. There are ethical rules for all types of research. In this training, you will learn about ethical rules for doing research with people.

Because people with disabilities have been hurt by researchers, some people with disabilities have a hard time trusting researchers. When people don't trust researchers, they often don't want to be in a research study. We'll talk more about this later. It is important to be extra careful to not hurt or take advantage of people with disabilities when they are in research.