

Introduction to Research

Let's start with what the word "research" means. Research is a process used to find out new knowledge or new information. It starts with an idea or a question. Research can be scientific experiments in a lab or studies with patients in a clinic. Research allows us to find new treatments and help patients. For example, the dialysis machines and medications we use today were created and tested through research— research that involved people like you!

Most often, the goal of research is to make discoveries that will help future patients. Research can be exciting and can lead to promising treatments, but like many things, it can come with challenges. Research can take a long time, and it doesn't always give clear answers. If you decide to participate in research, you may not see its effect on your own medical care, but it could help others in the future.

Many people think about medicines when they hear the word research. As a dialysis patient, you may take binder pills or blood pressure medicines. As clinic staff, you may give patients EPO or iron. Years of research went into making these medicines and thousands of patients, clinic staff and doctors made them possible by participating in the research studies that tested them. It was a TEAM effort.

Types of Research

Now, let's take a moment to talk about types of research. There are a lot of different types of research. There are studies that test new medicines to treat symptoms like itching and upset stomach; others about ways to stop cramping and blood pressure drops; and still others about how to increase the number of kidney transplants.

So far- we've talked about research that asks volunteers to do something like take a medicine or complete a task. You may hear this called a "clinical trial." A "clinical trial" is a type of study that tests health-related treatments or procedures. But, research is more than clinical trials. Research can include reviewing information from medical charts or asking people what they think or how they feel about a topic.

Research comes in all shapes and sizes. Studies can be small with a few patients at just one clinic or they can be big with thousands of patients from many countries. Studies can be short such as doing just one interview, or they can be long, where patients are followed over many years. Every study is a little different.

In general, research is how scientists and doctors answer questions and get information that they hope can be used to improve the lives of future patients.

Intermission - Patient & Nurse

Jason (patient): Wow! I didn't realize that there are so many kinds of research. I was in a study just a few months back where I talked about symptoms that bother me on dialysis. I was part of a group of patients that gathered together and the researcher asked us questions. I enjoyed hearing other patients talk about their symptoms and it felt good to know that sharing my story could help.

Nate (nurse): I once helped in a study by giving patients a study medication. I chose to help because I wanted to support patients beyond those in my own clinic. Jason, what made you want to participate?

Jason (patient): You know, Nate, I wanted to help other people who sit in this chair like me. I wanted to try and give them a better future, so maybe they wouldn't have to go through what I've gone through. I volunteered because the researchers took time to explain it to me and made me feel comfortable.

Nate (nurse): Let's go back to the video and learn more.

The IRB

If you are interested in participating in research, there are important things to know.

No matter the type...no matter the size...no matter the length...*All* studies are reviewed by experts not involved with the research itself. This group of experts is called an Institutional Review Board or "IRB" for short. The IRB makes sure that studies are safe and that people have a way to get out of the study if they want to stop. All researchers work from a written plan that they have to follow. The IRB must review and approve this plan *before* a study can start.

Participating in Research

If you are asked to participate in research, you should never feel pressure to do it. It's your choice. And if you do decide to participate, you can change your mind and stop at any time. Stopping or leaving a study will not affect your dialysis care.

It is important to know that research can have risks, and depending on the study, participants may experience discomfort or harm. Any and all risks must be explained to people before they sign-up to participate. Researchers and the IRB make sure that any risks are as small as possible and that patients know who to go to if they have problems or questions.

For most studies, you will be asked to sign a consent form. A consent form has information about the study's possible risks and benefits. It also tells you why the research is being done and how it might help others. This way, you know what you are signing up for. All researchers must also make sure that your information is kept safe and confidential. Only researchers can access your study information, no one else.

Conclusion

Altogether, this means that researchers must follow many rules to make sure you are safe and protected. Research has many steps that you never see.

Although research may have risks, and those risks differ depending on the study, there are many reasons why you might want to participate. For example, you might want the chance to learn from others' experiences or help future dialysis patients. Or, you might be interested in the research topic or just want to learn about new things. It is important to remember that some research does not lead to clear answers and many times research does not lead to a direct benefit for those participating in the study. However, studies that don't lead to clear answers can lead to new ideas! And, new ideas can lead to more research and eventual benefit for future patients.

But, even small studies may take a while. Research takes a lot of time. Researchers should tell you how long a study will take and when you should expect updates. But, if they don't – be sure to ask. It's important that you ask researchers *all* your questions. All questions are good questions.

The goal of research is to create better futures for people on dialysis, those who care for them in clinics, and those who help them at home.

Your involvement in research – as a patient, care partner, staff member or doctor – is important. YOU are an important member of the team.

Research is going on around us all the time. Today's research could help the patients of tomorrow have a better future.

Thank you & Acknowledgements

Jason (patient): Thank you for watching our video!

Nate (nurse): Hey! Even making this video involved *research*. Thank you to the more than 75 dialysis patients, care partners, clinic staff and doctors who gave us the ideas that shaped this video. It was a **TEAM** effort.



Scan this QR code or visit go.unc.edu/researchtoolkit to see the animated video and toolkit materials

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