

I AM MAKING DECISIONS ON BEHALF OF A PATIENT WITH COVID-19:

Should I consent for them to join a COVID-19 research study?



If you are responsible for making decisions for someone who cannot choose on their own, they may still be able to join a COVID-19 research study.

A research study:

- collects new information about health and disease.
- tries to answer new questions that researchers have.
- needs volunteers to sign up.

COVID-19:

- is a new disease caused by a type of virus called coronavirus.
- may cause some people to have symptoms like cough, fever, weakness, muscle and other pains, and breathing problems.
- can be mild, but it can also make some people very sick, and may lead to death.

Being in a COVID-19 research study is a choice.

Why are there research studies about COVID-19 right now?

COVID-19 is a new disease, so it is important understand more about:

- How the virus spreads.
- Why some people get very sick, and some people do not.
- Which treatments work best, and if they work for everyone.
- How to prevent new infections.

More can be learned about COVID-19 by joining a research study.

I make healthcare decisions for someone who is too sick to decide. What should I ask the research team before deciding what to do?

- ✓ Why is the study being done?
- ✓ What will happen if they join the study?
- ✓ Could the study help them? Could it help others?
- ✓ Could the study cause risks to them?
- ✓ Do we have to pay for them to be in the study?
- ✓ Will they be paid to be in the study?
- ✓ Will their personal and health information be protected?
- ✓ How long will the study last?
- ✓ Can they leave the study at any time?
- ✓ What will happen if they get hurt in the study?
- ✓ Who should I call with questions about the study?
- ✓ Will study results be made available?

What else should I consider before deciding for someone who is too sick to decide?

- You might consider whether the person for whom you are deciding would want to be in the study or not, and if the study might help them.
- You can talk to people you trust about the research study.
- You can change your mind at any time.

What happens if the person I am deciding for gets well enough to decide?

If a person's condition improves, they will be asked whether they want to stay in the study. They can choose to continue to take part or leave the study.