

Information in simple language:
Description of the clinical picture of adults with rare genetic syndromes

Dear patient,

We ask you: Would you like to participate in a study?

In this text you will get information about the study

Study means:

In a study doctors, for example, do research.

To do this, they need people who want to help them.

Another word for study is research.

Our hospital planned the study.

About 100 patients take part in the study.

Important: Your participation in the study is voluntary.

This means:

You are participating in the study.

No one is forcing you to do so.

You agree with the study.

You can always tell us: you do not want to take part in the study.

That is ok.

You don't have to say why you do not want to take part in the study.

If you do not take part in the study, you have no disadvantage.

This means:

You do not want to participate in the study

Nobody is mad at you, there is no damage.

Why is the hospital doing this study?

The doctors only know very little about the syndrome you have.

That is why doctors want to learn more about people like you.

What doctors learn in this study, they want to share with other doctors through articles, books and meetings.

Your personal data, for example your name, your address or your date of birth, will never be mentioned.

We replace your personal data with a code.

In difficult language this means: we pseudonymize your data.

This means no one can see to whom this data belongs.

The study

For this study we need your data.

Your health data, too.

Health data are for example: what disease you have.

Your family doctor, for example, has your health data.

The doctor from the study may get this data.

For the doctors from the study, it is an advantage.

In difficult language this means: you release your family doctor from the duty of confidentiality.

For this we need your consent or the consent of your legal guardian.

For this study, your doctor needs to fill out a questionnaire.

You do not have to do anything.

The risk of the study

You are participating in the study.

The study is checked.

The study is safe.

But things can happen in any study.

In this study, it could happen that someone cracks the code and finds out that you took part in the study.

The benefit of the study

You are taking part in the study.

You do not benefit from it.

Note: The study is over.

Then there is a result from the study.

The result can help people.

Costs

The study is free of charge

Privacy

Privacy means:

You decide who can use your data and for what reason.

Not all people may know your data.

Not all people are allowed to use your data.

Not all people are allowed to share your data.

There is a law for data protection.

We observe this law.

We need your data for the study.

We store your data only for the study.

We need your data only for this study.

For this we need your consent or the consent of your legal guardian.