



# Participate in research for children

## What is this form for?

The mission of the Ophthalmic Hospital is to treat the sick, as well as to improve the way they are treated. We can improve the way we treat illness through doing research. Research aims to solve problems. When a solution to a problem is found, it is sometimes possible to make new medicines or discover ways to better help sick people.

To solve these problems, we need to access the information that is collected during your visits at the Hospital. This information is the information that relates to you (your age, your health problems, the images of your eyes, etc.). This is called health data.

This information form explains how we do research at the Hospital. It explains how you can help us to continue to do better.

## How can you take part in research?

You can help us improve care by allowing us to use your health data in research projects. This is the data that has been collected by the doctor during all your visits to the Jules-Gonin Ophthalmic Hospital, as well as the data that will be collected in the future.

## Do I have to take part in research?

It is your decision. You are free to say yes or no, but it is important that you communicate it.

**You will be as well taken care of whether you participate or not.**

## Even if I agree now, can I change my mind later?

You can change your mind at any time and without explanation. Simply call us or write to us at the address given at the end of this form.

In this case, we take the necessary steps to ensure that your health data is no longer used in the new research. **Withdrawing consent has no effect on the care given to you.**

## How can I communicate my decision?

You can complete and sign the attached consent form with your parents.

Your decision and that of your parents remain valid in the future until you are 18 years old, unless you and your parents decide to change your decision.

If you sign by checking "NO", your health data will not be used for research.

If you do not sign the consent form, in exceptional cases, the hospital still has the right to request special authorisation from the Research Ethics Committee to use your data without your consent. It is important that you make your choice.

## Where are health data stored?

Health data is kept in a safe location at the Hospital and it is protected by law. Only the employees of the Hospital (e.g. your physician) can access it and know that this data is yours.

## How are research data protected?

If your data is used in the research, all the information about your identity (your surname, forename, etc.) is replaced by a code (e.g. AZ8492).

The key to the code is kept by a person who is not participating in the research project. If a research project allows for the discovery of important results for your health and you need to be informed about it, a group of hospital experts can unlock the code to give this information to you.

In rare cases, the data is anonymised. In this case, the code key is destroyed and no-one can know that this data is yours.

Only people authorised to work on research have the right to use your data at the Hospital, in Switzerland or abroad. Before starting, each study must be recognised and approved by a group of people dedicated to protecting your rights: this is called the ethics committee.

## Will you be informed of the research results?

Not usually. In principle, there will be no results which concern you directly, because they are very general. In rare cases, researchers may find a result that is important to your health. In this case, you and your parents would be informed, as long as your data has not been anonymised.

## Does consent remain valid when you come of age?

As soon as you turn 18, we'll ask you again for your opinion on general research consent.

If you are under 14 when you sign the consent, your data will no longer be able to be used for research without your new consent when you turn 18. The same rules apply if your parents or your legal representative alone signed the declaration of consent during your adolescence.

If you gave your consent during your adolescence (between 14 and 17 years old), and you do not respond to our request, your data may still be used for research.

## Who do you contact?

If you have any questions, don't hesitate to ask your parents. They can contact us at the address below or visit our website. You can also discuss it with the doctor during your consultation.

When your parents have completed and signed the consent, they can give it to the doctor or the secretary for the service where you had your visit, or send it to us by post at the following address:

**Centre d'investigation clinique CIC**

**Fondation Asile des aveugles**

Avenue de France 15

P.O. Box 5143

1002 Lausanne, Suisse

Telephone number: **021 626 82 11**

[www.ophtalmique.ch/consentement](http://www.ophtalmique.ch/consentement)

**Do you have questions?**

If you do not understand words on this form, or if you want to ask questions, you can ask the doctor during your consultation and your parent(s) or guardian(s).

