



# Participate in research

## Information on the reuse of health data for research purposes

Our ability to diagnose and treat diseases has improved dramatically over the past decades. These advances have been made possible by the sustained effort of medical research in which several generations of physicians, scientists and patients have actively participated.

An important part of this research relies on the reuse of the clinical data of patients from medical records, such as retinal images, laboratory test results or response to medical treatments.

This information brochure tells you how you can contribute to medical progress. It provides you with explanations on the protection of your data and your rights.

We thank you for your interest and attention.

## How can you contribute to research?

You can contribute to research by agreeing to have your data reused for research purposes. The data includes the data that has been collected in the past, as well as the data that will be collected for your care during your stays and consultations at the Jules-Gonin Ophthalmic Hospital, or with your referring physician, current and future.

## Your consent is voluntary

It remains valid for an indefinite period or until its withdrawal. You can withdraw your consent at any time without having to justify your decision. To do this, you just need to inform our clinical investigation centre at the address indicated on the back of this leaflet.

If you sign the declaration of consent by checking "NO", your clinical data cannot be used for research. If you do not sign it, the law provides that your data may be used in exceptional cases if the relevant ethics committee gives its special authorisation. It is therefore important for you to make your choice.

Your decision has no effect on your medical treatment.

## What happens if you withdraw your consent?

In this case, the copy of your data intended for research purposes will be deleted, subject to legal requirements. Your data is also no longer available for new research projects. This does not apply to data that has already been used before the withdrawal of your consent.

## How is your health data protected?

The data is recorded at the hospital and protected in accordance with the legal requirements in force<sup>1</sup>. Only authorised employees of the hospital (e.g. physicians in charge of your care), have access to your data in its identified form.

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<sup>1</sup>In particular, the law on research on human beings and the law on data protection.

If your data is used for a research project, it will be encrypted or anonymised.

- The term “encrypted” means that all personal information (e.g. your name or date of birth) is replaced by a code. The key to knowing which code corresponds to which individual is kept securely by a person not involved in the research project. People who do not have the encryption key cannot identify you.
- The term “anonymised” means that the link between the data and the individual is permanently broken. According to the law, data is said to be anonymised when it can no longer be linked to a specific person without making a disproportionate effort. In principle, it is no longer possible to identify the data subject, although absolute anonymisation cannot be guaranteed. Once the data has been anonymised, its use cannot be prevented in the event that the data subject withdraws their consent. They also cannot be informed of any research results that are relevant to their health.

The majority of research projects use encrypted data, especially when it can generate results that are relevant to the health of the data subjects.

The rights relating to the protection of your data in the context of research are the same as in the context of healthcare, in particular the right to access your personal data.

## Who can use your health data?

The data can be used by researchers who have received authorisation from the relevant research ethics committee. Research projects are carried out in the hospital or in collaboration with other public institutions (e.g. other hospitals or universities) and private entities (e.g. pharmaceutical companies) in Switzerland or abroad. The transmission of data abroad for research purposes is only possible if an adequate level of protection is guaranteed<sup>2</sup>.

## Will you be informed of the research results?

In principle, research conducted with your data will not reveal any individual information relating to your health. In rare cases, however, it could happen that relevant results are discovered where treatments or preventive actions are available. In this case, you will be informed.

## Does your participation incur costs or financial benefits?

Your participation does not incur any additional costs for you or your insurance. The law excludes the marketing of data. Therefore, no financial benefit will be generated for you or for the hospital.

## Declaration of consent

You can communicate your decision to us by completing and signing the declaration of consent for the use of health data for research purposes.

When you have completed and signed the declaration of consent, you can give it to the physician or the secretary for the service where you are being examined, or send it to us by post at the following address:

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<sup>2</sup>The guarantee is provided either by the data protection legislation in the destination country or by an international body

Centre d'investigation Clinique, Hôpital ophtalmique Jules-Gonin,  
Av. de France 15, CP 5143, 1002 Lausanne

If you have any questions or would like additional information, please do not hesitate to write to us at the above address or contact us:

By phone: [021 626 82 11](tel:0216268211)

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

## The Swiss Eye Disease Registry

Hospitals specialising in ophthalmology, ophthalmologists and treating physicians work together to improve patient care. The aim of the Swiss Eye Disease Registry (SMO) is to collect and analyse the images captured by these professionals on a large scale and in an encrypted manner in order to advance research on eye diseases. This first-rate resource will help in the development of new therapies and preventive measures. Your ophthalmic images and health data can be transmitted to the Swiss Eye Disease Registry where they will be stored and processed in an encrypted and secure form in a dedicated research space in Switzerland. The conditions for accessing images and their use are described in the regulations of the Swiss Eye Disease Registry ([ophtalmique.ch/consentement](http://ophtalmique.ch/consentement)).

## How can I manage access to my data?

Once you have decided (yes or no) on the reuse of your data using the general consent form, a computer link will be sent to you by SMS via the contact details provided during your admission to the hospital. Through this secure invitation link, you can create an account on the EyeConsent web application. This platform allows you to view your medical images and manage researchers' access rights to them dynamically, depending on the research projects. That means that you can give and/or withdraw your consent to the use of your data (including general consent) for studies via this interface, simply with the click of a button. The list of approved and active studies that need access to registry data is also made available through this application.

## Why is the data in the register encrypted and not anonymised?

By definition, anonymised data does not allow any link between your identity and your data. In order to allow you to have an overview of who is accessing your data, it is necessary that this link be preserved. Thanks to the connection between you and us through the EyeConsent app, you are always able to manage access to your data.

