

General Consent: Information sheet

Further use of health-related personal data and biological material for research purposes

Dear
patient,

In the course of your hospital stay, health-related data is collected and biological material perhaps removed (blood samples and other bodily fluids as well as tissue samples). This biological material in combination with the data is also valuable for medical research. For this reason, we would like to request your consent to use this material and data for research purposes.

Your consent for research

By giving your consent, you allow researchers to evaluate the data using scientific methods and conduct tests on the samples obtained from you. The consent relates to data in our hospital on your health or person. This includes, for example, entries in the medical records on the course of the disease and the treatments carried out, the results of imaging or laboratory investigations, information on the hereditary predisposition for certain illnesses (genetic data) and also personal details (e.g. age, gender). The samples are biological materials that have already been removed, such as blood, urine or tissue biopsies, and are no longer needed for the purposes of diagnosis or treatment. You may be asked for your consent in this regard on a further occasion in our hospital. For example, if the hospital responsible for you wishes to take further samples from you or if a particular problem is to be investigated in scientific terms. If this is the case, the team responsible for your treatment will inform you.

Protection of data and samples

The use of data and samples and their transfer to researchers in Switzerland and abroad are subject to strict rules. Only a few people are entitled to see data on your case history. These are people who are responsible for your treatment or have permission to see the data in the context of a research project.

Data used for research purposes must be **encrypted** as quickly as possible; this means that all information indicating a person's identity, such as their name, date of birth, insurance number etc., are replaced by a code. Therefore, only people with access to the key (a document combining the code and the name) can identify the person.

The samples (biological material) are stored securely in a biobank. A biobank is a systematic collection of samples and connectable data under clearly defined conditions. Samples and genetic data may only be passed to researchers in an encrypted or anonymised form. Anonymised means that all information which can identify a person or other item is made unrecognisable or deleted so that you can no longer be identified.

Disclosure of your data and samples

If data and samples are disclosed to researchers **outside** our hospital in encrypted form, the key remains in our hospital where it is kept securely by a department that is not involved in the research project. In the case of research outside Switzerland, the organisation involved must guarantee that at least the same requirements for data protection as those of Switzerland are met.

In addition, research projects must be approved by the relevant ethics commission. The commission examines whether the project and its execution are scientifically and ethically justifiable and whether the legal conditions, particularly those relating to data protection, have been observed.

Research findings

The findings of research projects using data and samples generally only contribute to improved medical care for future patients. If the results are relevant to your personal health, you will be informed of this whenever possible (this is not possible for research using anonymised samples). However, such situations occur only rarely.

The assignment of data and samples for research does not give rise to any entitlement to participation in potential profits which could arise from the results. **Neither** the patient **nor** the health insurance company incurs **any costs** from the research projects.

Your rights

Your consent is voluntary and in principle applies without restriction. However, you have the right to withdraw your consent at any time without giving reasons (**revocation**). If you wish to do so, please contact the hospital that is providing the treatment. If you withdraw your consent, the data and samples will no longer be issued for research projects.

No matter your decision, it will have no influence on the patient's medical care.

However, it is very important that you decide either for or against the additional use of your data and samples for research purposes. To this end, please sign the consent form and put a cross in either the Yes or No box.

If you still have questions on the further use of the data and samples for research purposes, please contact the attending doctor or visit our website:
www.hirslanden.ch/forschung

General consent: Declaration of consent

for the further use of health-related personal data and biological material for research

Family name and first name
of the patient

Date of birth:

I confirm that

- I have received the information sheet accompanying this declaration of consent and I feel that I have been adequately informed.

I give my consent that

- the health-related data (including genetic data) and biological material in the form described above may be used for research purposes.

Yes

No

By granting access to the health-related data and samples, you are making a valuable contribution to biomedical research.

Thank you very much.

Place

Date

Patient's signature