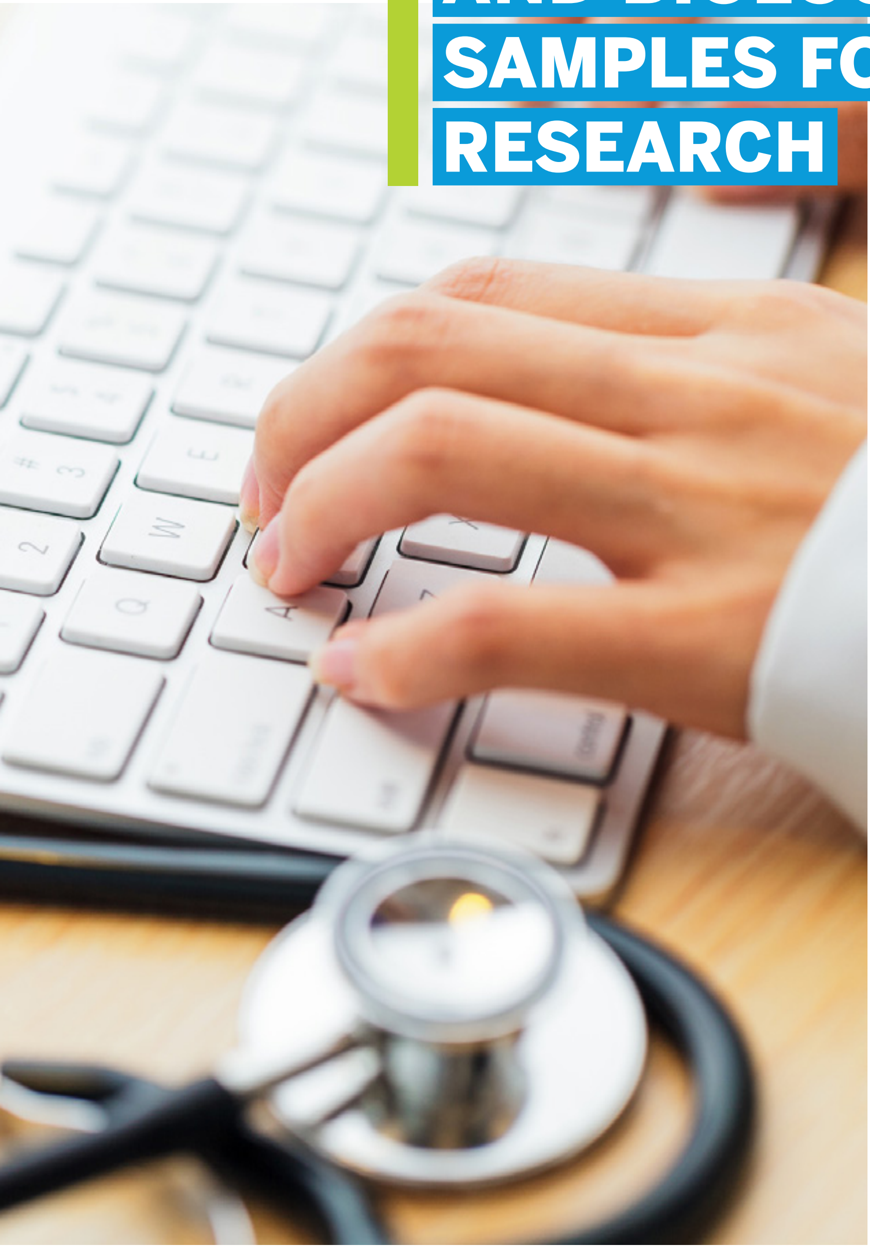
Research committee KSW

FURTHER USE OF PATIENT DATA AND BIOLOGICAL SAMPLES FOR RESEARCH



Kantonsspital Winterthur

Dear Patient,

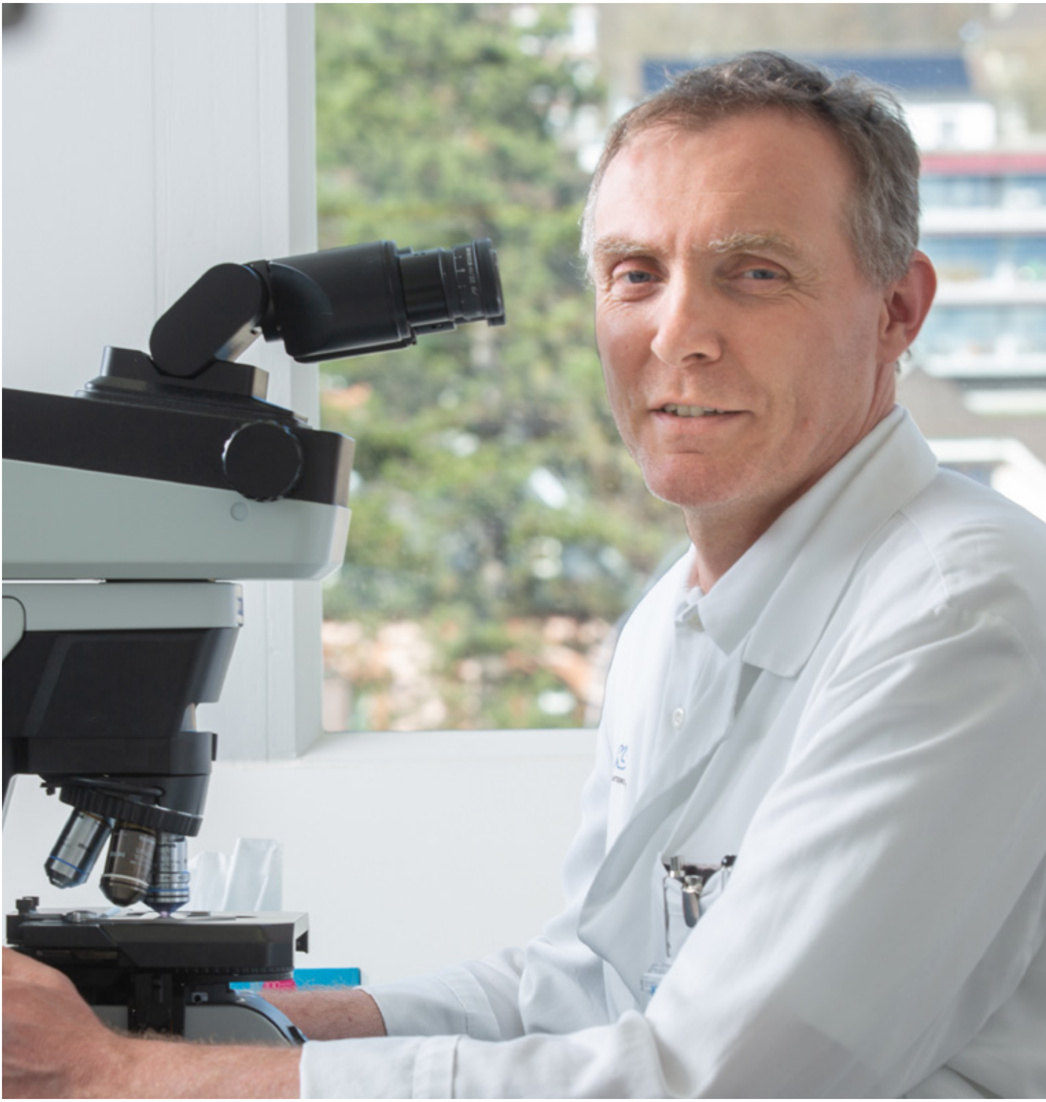
There have been great strides made in the recognition and treatment of illnesses over the last few years. They are primarily due to medical research. Nevertheless, there is still potential for improvement in many fields.

Our hospital is determined to ensure that further new insights can be gained as they improve our understanding of illnesses. This will help develop new treatments and improve existing ones.

Under Swiss law, we may use your patient data for research as long as we have your written consent. The same is true for biological samples, such as blood, urine, and tissue.

This brochure gives you more detailed information on how you can contribute to the advancement of medicine by providing your consent.

We thank you for your interest and your help in this regard.



PD Dr. med. Jeroen Goede
President of the Research Committee KSW

Admission and consent

You may have been admitted to our hospital for a variety of reasons. Have you come to see us because you are in pain? Or do you need a special examination or treatment? Your doctor is obligated by law to document the exact course of your treatment in a medical file. Sometimes blood, urine or other samples from your body are needed to identify and understand certain diseases. This medical file and the results of the examinations are stored for at least ten years after the treatment has ended. Any remaining samples are normally disposed of after the examination has been completed.

You have the option to make the patient data in your medical file and any remaining samples available for research. With your help, new insights can be gained with this data in different projects.
Your consent is voluntary and has no influence on further treatment.

If you agree, researchers may use your patient data and samples. As long as you do not revoke your consent, it is valid for all treatments (present and future) at our hospital.
You may change your mind at any time and withdraw this consent. You do not need to provide any reason for doing so. From this time onwards, we are no longer permitted to use your patient data and samples for research purposes.

Example from a typical hospital day

Mr Keller is referred to Kantonsspital Winterthur by his family doctor. He has suspected type 2 diabetes mellitus. During his first visit to the hospital, various information is recorded concerning him. In addition, he also receives the documentation on the further use of his patient data. Mr Keller is in agreement. He fills in the form accordingly and signs it. His consent is recorded in the hospital's clinical system.

A doctor questions Mr Keller about his symptoms and performs an initial examination. In the course of this examination, Mr Keller must provide a blood and urine sample. The doctor enters all his details into the patient file in the clinical system. Finally, the all-clear is given; Mr Keller does not have diabetes. Then he can leave the hospital.

Safety of your data and samples

There are different types of data. Health-related personal data includes, for example, your name, your address or the reason for your admission to our hospital. To simplify matters, we will refer to this information as patient data.

Genetic data is considered to be all information about the genetic make-up of a person, and such data is gained through genetic examinations. The law aims to provide special protection for genetic data and biological samples. For this reason, researchers only ever receive such data in anonymous or encrypted form. The encryption may only be lifted in special cases. This can be necessary for the protection of your health or when it is required by law.

Under Swiss law, your data is treated as strictly confidential. Only authorised people from our hospital may view the data in your case history. These persons are either involved in providing you treatment or have been authorised by the ethics committee to view your data for an approved project. If data are used for research projects, they must be encrypted as soon as possible.

Your samples are securely stored in a biobank. A biobank is a collection of human samples that include pertinent medical information.

What does "encrypted" mean?

Encrypted means that all information which could identify you (such as your name, date of birth, address, etc.) is replaced with a code (key).
People who do not know this code cannot draw any conclusions on your person. The key remains permanently at Kantonsspital Winterthur.

What does "anonymised" mean?

Anonymised means that all information which enables conclusions to be drawn on your person is completely removed. After the anonymisation, it is no longer possible to determine which data stems from which patients.

Evaluation and further use

While you are being treated at our hospital, your data and samples are available in unencrypted form. This enables us to provide safe treatment and to take quick action in cases of emergency. The unencrypted data is part of our clinical system, which is extremely well protected. Only authorised people, such as your doctor, have access to it. They are all obligated to keep these data and samples confidential.

With your consent, such data and samples may be made available for research purposes. Research may only be undertaken if a cantonal ethics committee has provided the requisite permit. The researchers may either work at our hospital or in another company. This can be another hospital, a university or even a company.

For research conducted in foreign countries, the data protections must, at a minimum, meet the same requirements as in Switzerland.

Example from a typical hospital day

Three years after Mr Keller's treatment, a research team conducts a project on type 2 diabetes mellitus. Thereby, they require new laboratory results to help them recognise type 2 diabetes mellitus earlier. In the future, this would provide patients with a quicker diagnosis and enable earlier treatment as a result. The research team has obtained the consent of the responsible ethics committee. It now starts to evaluate different patient data, including that of Mr Keller. His data has been encrypted and appears in the research database under the code 015_46. All of Mr Keller's personal details have been removed.

Future uses

After the end of a research project, the results are published, where possible, in specialist magazines. Or the doctors present them at congresses or in training courses. Thus, the results are of great importance for advancement in medicine. These new results enable ongoing improvement in the diagnosis and treatment of illnesses.

Sometimes results from a research project can be important for your own health. If possible, we will inform you regarding these results. When conducting research with anonymized data, however, it is no longer possible to trace this data back to any specific person.

Neither you nor our hospital can benefit financially from any profits resulting from the development of a new medication, for example. The hospital is forbidden by law to earn money with your data or samples.

Example from a typical hospital day

The research team was successful. A new laboratory result was found which could make the diagnosis of type 2 diabetes mellitus quicker and safer. This was possible because Mr Keller and other patients made their data available for the aforementioned research. The results of the study will be published in a specialist magazine and confirmed in further studies.

In this way, new patients with suspected type 2 diabetes mellitus will benefit from a quicker diagnosis and – if necessary – from starting treatment earlier.

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Contacts

If you have any further questions, or you would like to revoke your consent, please contact:

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General consent, Version 8

Approved: Cantonal Ethics Committee, Zurich
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