

Together we take research one step further

Information regarding the use of
patient data and samples





We are passionate about research and our hospital.

We take pride in serving our
researchers and patients with
competence and quality.

Dear Patient

The diagnosis and treatment of illnesses has progressed significantly in the last few decades. This is the result of long-standing research in which physicians, scientists and patients of several generations have actively participated.

The University Hospital Basel considers itself to be not just a treatment center, but also an important link between research and patients.

Only with your cooperation can we acquire new knowledge in different medical fields and continuously improve diagnosis and treatment options.

In accordance with Swiss research legislation, it is mandatory for us to have your written consent in order to use information regarding your illness or samples collected in the context of your treatment for research purposes.

This brochure contains information on how you can contribute to medical progress.

We would like to sincerely thank you for your interest and your support.

Prof. Christiane Pauli-Magnus
Head of the Department of
Clinical Research
Head of the Clinical Trial Unit

Prof. Mirjam Christ-Crain
Head of the Department of
Clinical Research
Deputy Chief Endocrinology

Your consent

During your stay at the University Hospital Basel, we will ask you whether the information regarding your illness and samples that are collected for treatment purposes can be made available for research purposes. Your data will only be used in coded or anonymized form for research purposes. This means it will not contain your name or any personal information. We will provide you with an information sheet on this topic, which summarizes the most important facts.

You will then inform us of your decision in writing by signing a consent form. Your decision is voluntary and will have no effect on your treatment. If you consent, the data concerning your health and your samples can be used in the future for research purposes.

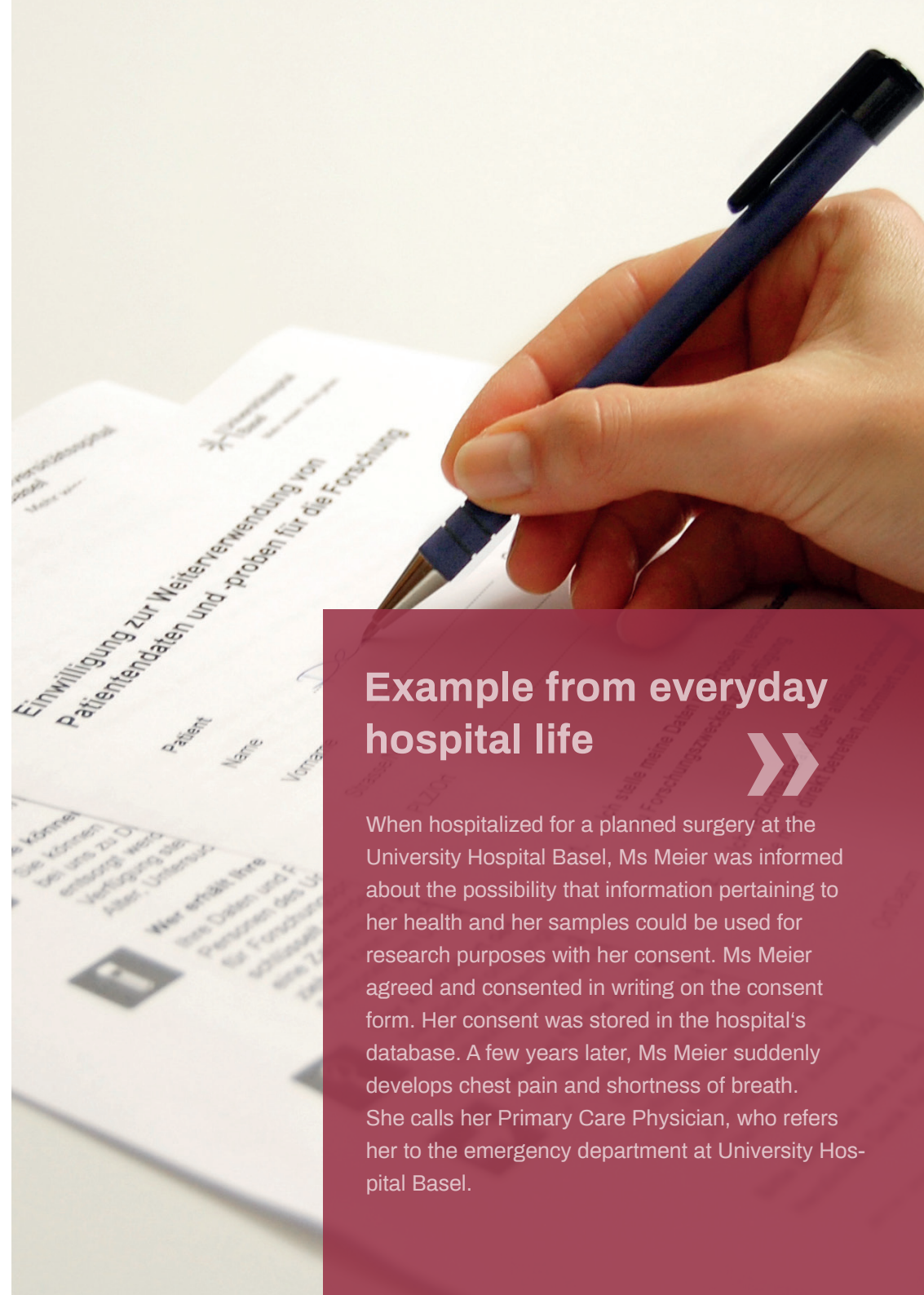
Provided that it is not withdrawn, your consent applies to all data and samples, which have been collected previously or will be collected at the University Hospital Basel. However, if you withdraw your consent, data concerning your health and your samples will not be available for new projects from that date. You do not have to justify your decision.

Please email the address below to withdraw your consent:

klinischeforschung@usb.ch

or write to the following address:

Universitätsspital Basel
Departement Klinische Forschung
Attention: Clinical Research
'Schanzenstrasse 55, CH-4031 Basel



Example from everyday hospital life



When hospitalized for a planned surgery at the University Hospital Basel, Ms Meier was informed about the possibility that information pertaining to her health and her samples could be used for research purposes with her consent. Ms Meier agreed and consented in writing on the consent form. Her consent was stored in the hospital's database. A few years later, Ms Meier suddenly develops chest pain and shortness of breath. She calls her Primary Care Physician, who refers her to the emergency department at University Hospital Basel.

A patient is lying on a hospital bed, partially covered by a light blue patterned sheet. A robotic arm with multiple joints and a white cable is positioned over the patient's head and upper body. The background is a solid dark red color.

In the emergency department >>

In the emergency department, a physician asks Ms Meier about her symptoms and carries out a physical examination. The symptoms indicate an acute myocardial infarction. Therefore, a blood sample is collected and special additional examinations are carried out. The all-clear is given after a few hours. The results do not confirm the suspicion of myocardial infarction. After a brief observation period, Ms Meier can leave the hospital.

Examination and sample-collection

Your stay at the University Hospital Basel can have various reasons. For example, it may be that you are here to find the cause of your symptoms, to undergo a specific examination or to receive medication or a surgical treatment. Usually, your medical history will be recorded and samples will be taken, where necessary. Both can be made available for research purposes with your consent.

Additional examinations are often necessary for your treatment, such as

- taking a blood / urine or tissue sample.
 - carrying out an X-ray or CT.
 - carrying out an organ examination, for example a gastroscopy or colonoscopy.
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Your medical history and your examination results are usually archived when you leave the hospital. Some samples are disposed of (for example blood samples), and others are routinely stored (for example tissue samples). With your consent, your samples and your particular medical history can supply valuable information to answer new research questions.

Evaluation and further use

During your hospital stay, your data and samples will be available in an uncoded format. Only authorized and clearly designated persons at the University Hospital Basel, like your physician for example, have access to the uncoded data and samples. All these persons are bound by professional secrecy. If your data and samples are used in a research project, they must be coded or anonymized by the University Hospital Basel.

Coded means that all information that can be traced back to you, such as your name or your date of birth, is replaced by a code. The code must always remain at the University Hospital Basel. Persons who do not have the code are not able to identify you.

The researchers may work in Swiss or international institutions such as hospitals, colleges or pharmaceutical companies. Research projects are diverse and might include genetic analyses. However, outside of Switzerland the legal requirements regarding data protection must be at least as high as in Switzerland.

In addition, research projects with coded data must be approved in advance by the competent ethics committee. This does not apply to research projects involving anonymized data and samples. In case of anonymization, the link between the biological material and/or associated data and the participant is permanently removed, so they can no longer be traced to a specific person.

Quicker diagnosis thanks to research



Two years after Ms Meier's treatment, there is ongoing research concerning new blood parameters that would allow quicker differentiation between harmless and dangerous chest pain. This would spare future patients a lot of uncertainty and waiting until they receive a conclusive diagnosis. Following approval by the ethics committee, Ms Meier's data and those of other patients with the same symptoms are put together into a database and evaluated. Ms Meier's data and samples are given the code 002_13 and all personal information is removed from the research database.



Future benefits

The results of research projects are generally published: they are instrumental for advances in medicine. The knowledge gained from research allows us to better diagnose existing and future illnesses of patients and contributes to continuous improvement in their treatment.

Research carried out with your samples and data will generally not reveal any individual information about your health. If research results might be relevant for your own health and clinical action might be possible, we might contact you.

Neither you nor the University Hospital is entitled to a share of the profits, for example from a new medication. It is legally prohibited for the University Hospital Basel to make money by selling your data and samples.

Research for future generations



The data and samples made available by Ms Meier and other patients have led to important findings. A new laboratory value was found that allows a quicker and more reliable differentiation between an acute myocardial infarction and harmless chest symptoms. The results will be further confirmed in subsequent studies. Future generations of patients will benefit from this new knowledge by receiving more rapid diagnosis and treatment.

Please email the address below should you have any further questions:

klinischeforschung@usb.ch

or write to the following address:

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Attention: Clinical Research
Schanzenstrasse 55, CH-4031 Basel

You will find our homepage at
www.unispital-basel.ch/dkf

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