

Information sheet on the further processing of biological materials and health-related personal data for research

Version 1.2, May 5, 2015

Dear patient,

We hereby invite you to contribute to medical research.

Background

Every hospital is required to make and store records for its outpatients and inpatients. This documentation contains health-related data collected during treatment (e.g. blood pressure readings, lab results, responses to questionnaires, etc.). In the course of your treatment, you may also provide materials from your body, such as blood or urine. Your physician may also take samples of your skin or other tissue. A test may be performed that produces genetic data (for example, to determine whether you are genetically disposed to a certain disease).

We would like to use all of these data and materials for medical research once they are no longer needed for your treatment. For this reason, we ask that you consent to the use of these data and materials for research purposes under strict conditions (compliance with the Human Research Act, data privacy). By doing so, you will be making a valuable contribution to advancements in medical research, and we thank you for this.

Your rights

The release of materials and data in encrypted or unencrypted form for further processing for research purposes is voluntary (the only exception is the further processing of your non-genetic personal information in anonymized form, which does not require your consent or approval by the cantonal ethics commission). No one will pressure or persuade you to do so in any way. If you opt to release the data and materials, you are entitled to withdraw your consent at any time. You are not required to disclose your reasons for refusing or revoking this release. Your decision will not affect your treatment.

If the findings from a research project are relevant to your health and we are able to trace the data back to you, we will be pleased to inform you of these findings if you request this.

Confidentiality and protection of your materials and data

Your materials and data are treated with strict confidentiality. This data is part of the hospital information system, which is highly secure and has strictly regulated access. The materials are stored securely in a biobank. Each biobank has a framework of rules governing safekeeping and access.

We are permitted to provide materials and genetic data in anonymized or encrypted form only. Anonymous means that information such as the name or address is made unrecognizable or deleted to eliminate the possibility of tracing the identity of the person.



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In the case of encrypted data, we replace this information (e.g. name, age, address) with a code and provide only the researchers with the code. The key (the list that connects the code with the name) is kept under secure and strict safekeeping conditions at UniversityHospital Zurich (USZ). Researchers cannot link the materials and data to your identity. This encryption can be removed in specific cases only, e.g. for the protection of your health, your rights or when required by law.

Materials and genetic data may also be released to third parties outside University Hospital if it is in anonymized or encrypted form. However, it must be used for research purposes only in compliance with the applicable data privacy regulations. The key is always kept here at USZ.

Your consent therefore permits research to be carried out using non-genetic data in unencrypted form. Only the few people working on the project and who absolutely need this data to carry out their work have access to this data. If requested, the non-genetic data can also be provided in encrypted/unencrypted form to third parties outside of USZ for research purposes provided this is done in compliance with the applicable data privacy regulations.

Support in research

The materials and data are permitted to be provided for research purposes only. Research is permitted to be carried out only when approved by a cantonal ethics commission in accordance with the Human Research Act. We therefore make materials and data available exclusively for approved research projects. These projects may lead to improvements in the treatment of future patients.

Contact

Please contact your attending physician if you have any other questions concerning the further processing of materials and data for research purposes or if you wish to revoke your consent.

Written revocation of your consent can be sent to the following address:

UniversityHospital Zurich
Patientenaufnahme "Einwilligung Weiterverwendung"
Rämistrasse 100
8091 Zurich
Switzerland



Declaration of consent

Patientenetikette / patient label

for the further processing of biological materials and personal genetic data in encrypted form as well as non-genetic personal data in unencrypted form for research purposes.

Last name/
first name:

Date of birth:

I hereby consent to

- biological materials from my person and genetic data about me in encrypted form – made available through medical treatment or otherwise – and
- health-related non-genetic data about me in encrypted or unencrypted form – made available through medical treatment or otherwise – being further processed for research purposes now and after my death.

Yes

No

I acknowledge that

- I have received the clarification document (version 1.2 dated May 5, 2015) accompanying this declaration of consent;
- I have been informed that my consent is voluntary;
- I have been sufficiently informed of the further processing of biological material and health-related data for biomedical research;
- I know that my materials as well as genetic and non-genetic data can be used for research unless I revoke this consent;
- I know that I am permitted to revoke this consent at any time without providing a reason;
- I know that my materials and data are protected;
- I know that my materials and data may be passed on to third parties for research purposes.

I wish to be informed about the research findings if they provide conclusions about my health and/or treatment.

Yes

No

Place

Date

Legally binding signature of the patient(s)

Legally authorized representative(s)

