



## Further use of health-related data and biological samples for research and teaching: information and declaration of consent

Dear Patient, Dear Parents,

### **Our request in brief**

The University Children's Hospital Zurich keeps a medical history file for each patient. This file contains a record of all the medical details of your child.

Laboratory samples are frequently taken as well, such as blood or tissue.

The data in the medical history file and the laboratory samples are very valuable for the fields of research and teaching.

► **We kindly request that we are able to use the data and samples appertaining to your child for the purposes of research and teaching.**

We shall treat the data as strictly confidential and comply with the legal provisions concerning data protection at all times.

### **Why are we asking you?**

In recent decades, the recognition and treatment of diseases has made huge progress. We owe this to medical research that has involved the participation of doctors, scientists and patients of every age.

Medical research relies heavily on data from patients' medical history files. This includes, for example, results from laboratory analyses as well as data regarding a particular treatment, or information on hereditary predispositions to certain diseases. Biological material that was taken during a hospital stay and is no longer needed for diagnostic purposes is also very valuable for research. This includes blood, urine or tissue samples. To enable further progress to be made in the field of medicine, we are asking you for your personal contribution.

### **What does your consent mean?**

If you provide your consent, your child's health-related data (for example, age and test results) and remaining samples (for instance, urine, blood or tissue) will be made available to the research and teaching. The consent applies to all the data that has already been collected in the hospital or will be collected in the future, and to all samples.

Of key importance: your consent is voluntary. Your decision for or against the further use of the data and samples has no influence on the medical treatment. The consent is valid for an unlimited period of time as long as it is not withdrawn (revoked). You can withdraw your consent at any time by contacting the address below, without providing any reasons. After revocation, the data and samples can no longer be used for any new research projects. There will be no additional costs either for you or your health insurance provider.

### **How are the data and samples protected?**

Your child's data and samples will be processed and protected in the hospital according to the statutory regulations ("medical confidentiality"). Only authorised hospital staff, such as attending doctors, are able to access the unencrypted data from your child's medical history and have access to the unencrypted samples.

Research projects are always reviewed by the responsible ethics committee. When researchers use the data for research projects, the data is copied directly from the medical history and then encrypted or anonymised. Encryption means that all personal data (name, date of birth, etc.) are replaced by a code. Persons who do not have access to the encryption key cannot identify your child. The key shows which code belongs to which person. It is stored safely at the Children's Hospital Zurich. Anonymising means that the key is erased. Nobody (not even the children's hospital) is able to find out anymore that the anonymised data and samples are from your child.

It is also possible that your child's samples and genetic data are stored in biobanks. A biobank is a structured collection of various samples and data which is subject to strict security regulations. The samples and genetic data are only made available to researchers in encrypted or anonymised form.

**Who is able to use your child’s health-related data and samples?**

If you give your consent, your child’s data and samples will be available to researchers at our hospital in encrypted form. The data and samples can also be used in research projects that involve collaborations with additional public or private institutions, such as other hospitals, universities or pharmaceutical companies. The research projects may be carried out in Switzerland or abroad, and may include genetic analyses where appropriate. For research projects abroad, at least the same data protection requirements apply as those in Switzerland.

**Will you be informed about the results of the research?**


Research projects involving data and samples do not usually result in information which is directly relevant to your child’s health. However, if a result which is significant for your child is found and a medical measure is available, the Children’s Hospital may contact you. Once data and samples have been anonymised, it is no longer possible to contact you.

If you have any further questions or require additional information, please contact us at the address below:  
 Universitäts-Kinderspital Zürich, Forschungszentrum für das Kind (*University Children’s Hospital Zurich, Research Centre for Children*), Steinwiesstrasse 75, 8032 Zurich.  
 Studiensupport.FZK@kispi.uzh.ch /+41 44 266 71 11.

**Declaration of consent for the further use of health-related data and samples**

I am aware that this information sheet (version 2.2, 29 Dezember 2020) describes the provisions concerning the further use of the data and samples. I have read and understood this information. I was given the opportunity to ask questions, and these were answered satisfactorily.

*Please affix patient label or indicate PID (will be carried out by the hospital)*

	<b>Yes</b>	<b>No</b>
 <p>I hereby agree that my child’s health-related data and samples collected or taken during my stay at the University Children’s Hospital Zurich can be made available to research and teaching in the manner described.</p>		

Place/date

First name/name of patient  
in block letters

Signature of patient, if over 14 years old

First name/name in block letters

Signature of parent/legal representative

*Ausgefülltes Formular weiterleiten an: Spitalarchiv (Fach 97)*