UKBB
kompetent & menschlich

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Information Research Consent

Information about possible future use of patient data and samples for research

Substantial progress has been achieved over the course of the last decades in the identification and treatment of many diseases. Much of this progress is the result of long-standing medical research, which actively involved many generations of doctors, researchers and patients of all ages. In this sense, the University Children’s Hospital in Basel (UKBB) views itself not only as a treatment and service provider, but also as a research institution supporting excellent research for the benefit of children and adolescents.

Information on the illnesses of our patients or unused/left-over samples obtained as part of routine care can be the foundation for medical research. According to Swiss Law (Schweizer Humanforschungsgesetz – HFG) the patients’, or in the case of minors the parents’/legal guardians’, written informed consent is required to enable future use of such data and samples. We are therefore approaching you as part of your child’s registration procedure to provide you with the opportunity to let us know your preference.

To ensure medical treatment can make further progress, we kindly ask you for your contribution.

What does it mean if I give my consent?

By consenting to the possible future use of data and samples, you are indicating that you are happy with the following process: Samples (urine, blood, tissue) that are collected as part of patient care at UKBB for diagnostic or treatment purposes usually are discarded immediately after completion of all requested test. If you provide consent, these samples may be kept and made available for future medical research in an encoded (pseudonomised) form. Similarly, encoded (pseudonomised) data from the patient record (e.g. age, test results, family history) may be provided. By consenting you indicate that you are happy with the use of past and future data/samples in encoded (pseudonomised) form for future medical research. Your consent is voluntary and is temporally unlimited and can be withdrawn at any time. The medical treatment will not be affected by your decision.

How will the data and samples be protected?

The UKBB attaches great importance to adhering to legal requirements and data protection. All information provided by you about, family or illness will be treated confidentially. Currently and in the future, only certain authorized personnel, such as your treating doctor, will have access to your child’s/your complete medical record as part of medical management. If you consent to the use of your child`s/your data/samples for research, our hospital will use them only in an encoded form (pseudonomised). This means that all information that enables identification of your child/you, such as name or date of birth, is replaced by a code. The identifying information linked to the code can only be accessed by a very small group of guardians in charge of the encoding. Researchers will not be able to access this information and therefore would be unable to identify your child/you from the data they would be working with. This guarantees the protection of your child’s/your data at all times. This encoding will be guaranteed in all research projects, including collaborations with private or public institutions, such as others hospitals, universities, pharmaceutical companies.

Once sampling material (blood, urine, tissue) will no longer be needed for diagnostics or therapy, left-over material will be stored in an encoded way according to national biobanking guidelines (Biobankreglement). These left-over samples can then also be used in research projects for genetic analysis.

Who is in charge of evaluating whether future research is valuable, scientifically justified and ethical?
All research with encoded (pseudonomised) data and samples is subject to Swiss legal requirements and has to be approved prior to the start of a project by an independent ethics committee. In case of international research projects all legal requirements have to be compliant with the Swiss law.

What else is important?

- The patient and parents/legal guardians have the right to access their/ their child's patient record at any time.
- If you provide your consent, you will not incur any additional costs or charges.
- The hospital must not and will not make any profit from sharing of patient data/samples. Neither you nor the hospital will derive any financial benefit.
- The decision about consenting to possible future use of patient data and samples will not have any influence on medical care.
- The decision is entirely voluntary and can be revoked at any time without further explanation.
- Research projects with personal data/samples usually will not result in information with direct impact on health issues of the individual. If unexpectedly findings relevant for your child/your result from further use of data/samples, we will contact you.
- After revocation, the data and samples will no longer be made available for new research projects.

Should you change your mind in the future and wish to withdraw your consent, please contact:
Universitäts-Kinderspital beider Basel
Paediatric Research Center (Pädiatrisches Forschungszentrum)
Subject: Clinical Research (Klinische Forschung)
Spitalstrasse 33, 4056 Basel
or email pfz@ukbb.ch

Please indicate your preference on the informed consent form! We thank you for your commitment!