



Information about the use of health-related data for research purposes at SwissNeoNet

Dear Parents,

Our ability to diagnose and treat diseases has progressed significantly in recent decades. These advances are the result of long-standing medical research in which doctors, scientists and patients of several generations have actively participated. An important part of this research relies on patients' health-related data from medical history, such as results of laboratory analyses or therapy information.

This leaflet explains how you as a parent can contribute to medical progress and provides information in terms of data protection and associated rights of your child. Thank you for your interest and attention.

How can you contribute to research?

By signing the declaration of consent with «Yes», you are making your child's clinical data available for research purposes. Data include those that have been collected and will be collected during your child's hospital stay. Your consent is voluntary. It remains valid until your child is 18 years old or until withdrawn. You are entitled to withdraw your consent at any time without having to justify your decision. After withdrawal, your child's data will not be available for new projects. Your decision has no effect on your child's medical treatment.

How are your child's health-related data protected?

Data is stored within the hospital and protected in accordance with the applicable legal requirements. Only authorised employees from the hospital, e.g. physicians, have access to your child's uncoded data.

Your child's data will be securely transferred to SwissNeoNet. SwissNeoNet is the medical registry of the Swiss Society of Neonatology (www.neonet.ch). Its chief aim is to maintain and / or improve the quality and safety of medical care of babies through a coordinated program of research and quality control by the Swiss neonatology clinics. Apart from your child's date of birth, no other personal data such as name or address of her/him or you are transferred to SwissNeoNet.

If your child's data are used for a research project, they will be extracted from the registry and subsequently coded or anonymised. Coded means that all personal information such as your child's date of birth is replaced by a code. The key showing which code belongs to which person is kept safe by a professional who is not involved in the research project. Researchers who do not have the code are not able to identify your child. In case of anonymisation, the link between the associated data and the participant is definitely removed so that no specific participant can be reidentified. Anonymisation is irreversible.

Who may use your child's health-related data?

Data may be used by authorised researchers for research projects within the hospital or in collaboration with public institutions (such as other hospitals) in Switzerland and abroad. For research abroad, it must be ensured that at least the same data protection conditions are followed as in Switzerland. Research projects relying on your child's data have to be checked and authorised by the relevant, independent ethics committee.

Will you be informed about research results?

Research carried out with data will generally not reveal any individual information for your child's health as we perform observational research and do not test interventions. We however publish our findings in peer reviewed scientific journals (see swissneonet.ch).

Will there be any costs or financial benefit?

There are no additional costs generated. SwissNeoNet is non-profit and does not sell any data. Thus, no financial benefits will be generated for you, the hospital or SwissNeoNet.

If you have any questions or would like additional information, please contact us at the address below or visit our website at

www.swissneonet.ch

PD Dr. sc. nat. Mark Adams, Koordinator SwissNeoNet

Universitätsspital Zürich

Klinik für Neonatologie

Wagistrasse 12

8952 Schlieren

Declaration of consent for the use of health-related data for research purposes

.....
Patient's surname and first name

.....
Date of birth

I herewith agree that my child's health-related data collected during health care (ambulant or as an inpatient) will be made available for research purposes

YES NO

I understand

- the explanations about the further use of my child's health-related data for research purposes that are detailed in the information sheet ([version 3, August 2023](#)).
- that my child's personal data are protected.
- that my child's data may be used in national and international projects within the public and private sectors.
- that my decision is voluntary and has no effect on my child's treatment.
- that my decision is not limited in time.
- that I may withdraw my consent at any time without having to justify my decision.

.....
Place, date

.....
Parent's signature, if judicious

.....
Place, date

.....
Signature of legal representative, if required
(Name and relationship to patient)

Please contact your child's physician if you have further questions or if you wish to receive a copy of this form with signature.