

## Information about the use of health-related, non-genetic data for research purposes

Dear Patient,

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. The Arlesheim Clinic sees itself not only as a treatment centre, but also as a research institution of anthroposophic medicine for the benefit of patients. The research is dependent on collecting data from patients' medical records. By collecting this information from many individuals, we aim to assess the effectiveness of treatment methods applied in our institution. For this reason, we would like to collect medical, non-genetic data from your medical records (e.g. age, diagnosis, laboratory analyses, questionnaires, treatment, investigation results). This will be made available to researchers only in encrypted form (i.e. a form that makes it impossible to link the information to an individual patient).

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



Dr. med. Lukas Schöb, Medical Director

### How can you contribute to research?

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 It remains valid indefinitely or until withdrawn.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

### How are your 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 uncoded data.

If your data are used for a research project, they will be coded or anonymised. Coded means that all personal information such as your name or 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. People who do not have the code are not able to identify you. In case of anonymisation, the link between the associated data and the participant is definitely removed so that no specific participant can be reidentified.

### **Who may use your health-related?**

Data may be used by authorised researchers for research projects within the hospital or in collaboration with public institutions (such as other hospitals) and private entities (such as pharmaceutical companies), 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 data have to be authorised by the relevant ethics committee.

### **Will you be informed about research results?**

Research carried out with your data will generally not reveal any individual information for your health. In rare cases, research results might be relevant or significant to your own health and clinical action might be possible. In these cases you might be informed.

### **Will there be any costs or financial benefit?**

There are no additional costs generated. The law excludes commercialisation of data. Thus, no financial benefits will be generated for you or the hospital.

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

[www.klinik-arlesheim.ch/klinik-arlesheim/forschung](http://www.klinik-arlesheim.ch/klinik-arlesheim/forschung)

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