hôpital fribourgeois
freiburger spital

Participation in medical research

One-time general consent for the use of your health data and samples for research purposes

Dear Sir or Madam

You can play an important role in the future of medicine. Considerable progress has been made in our ability to diagnose and treat illnesses over the last few decades. This progress has been possible thanks to ongoing efforts in medical research, in which several generations of doctors, scientists and patients have been actively involved.

A large part of this research is based on the use of patients' clinical data in medical records, such as the results of laboratory tests, medical treatments or genetic predispositions. All biological material collected during the hospital stay that is no longer required for treatment (such as blood, urine, tissue samples) can be extremely valuable for research.

This document explains how you too can contribute to progress in medicine and provides information on how your data are protected and on your rights.

How can you contribute to research?

You can contribute to research by agreeing to your data and residual biological samples being retained, shared and reused for research purposes. The data and samples include those that have been collected in the past. They also include those that will be collected for your treatment during your current and future stays and consultations at the hôpital fribourgeois (HFR).

Your consent is voluntary.

It remains valid indefinitely or until it is withdrawn. You may withdraw your consent at any time without having to give a reason. To do so, simply inform the Medical Department of HFR; you can find their details at the end of this document.

If you do not sign the consent form or you sign it having checked "NO", your clinical data and biological samples cannot be used for research.

Your decision will not affect your medical treatment.

What happens if you withdraw your consent?

In this case, your data and samples destined for research will be destroyed, subject to legal requirements. From that point, they will no longer be available for new research projects.

How are your health data and your biological samples protected?

The data are stored at the hospital and protected in compliance with the relevant legal requirements[1]. Only authorised employees of the hospital, such as doctors treating you, have access to your data and samples in identifiable form.

Your biological samples are stored in biobanks. These ensure proper management of the samples and that they are linked with the data in your medical records. These samples and data may be use for your medical care as well as for research purposes. They are subject to security and quality standards (www.h-fr.ch/nos-recherches/consentement-general).

If your data and samples are used for a research project, they will be coded or anonymised.

- The term "coded" indicates that all personal information (such as your name or date of birth) is replaced by a code. The key that can be used to identify which code corresponds to which individual is held securely by someone who is not involved in the research project. People who do not have the coding key are unable to identify you.
- The term "anonymised" indicates that the link between the biological material or the associated data and the individual has been permanently severed. According to the legislation, data are considered anonymised when they cannot be linked to a specific person without excessive effort. In theory, it is no longer possible to identify the individual concerned even if complete anonymisation cannot be guaranteed. Once the data and samples have been anonymised, the individual concerned cannot withdraw their consent for the use of these data and samples. They can also no longer be informed of any results of the research relevant to their health. Likewise, the anonymised data and samples will not be destroyed in the event that consent is withdrawn.

The majority of research projects use coded data, particularly where they may generate results relevant to the health of the individuals concerned.

You data protection rights in the context of research are the same as those in the context of treatment, notably your right to access your personal data.

Who can use your health data and samples?

The data and samples may be used by researchers authorised by the responsible research ethics committee. Research projects are carried out at HFR or in collaboration with other public institutions (such as other hospitals or universities) and private entities (such as pharmaceutical companies) in Switzerland or abroad.

Sharing of data or samples abroad for research purposes is only possible if the data protection conditions in the country of destination are at least equivalent to those applicable in Switzerland.

Projects may include genetic analyses for research purposes. Any research project using your data or samples must be approved by the responsible research ethics committee.

[1] Notably the Federal Act on Research involving Human Beings and data protection legislation.

Will you be informed about the results of the research?

In principle, the research carried out using your samples and data will not generate any individual information concerning your health. However, in rare cases, relevant results could be discovered for which treatment or preventive actions are available. In this case, you would be informed.

If you do not wish to receive such information, please inform the Medical Department of hôpital fribourgeois; you can find their details at the end of this document.

Will your participation result in costs or financial benefits?

Your participation will not result in any additional costs for you or your insurance company. The law excludes commercialisation of data and samples. Consequently, no financial benefit will be generated for you or the hospital.

You can communicate your decision to us by completing and signing the consent form.

The consent form involves three steps:

A. After completing your last name, first name and date of birth, indicate whether you agree to or refuse the use of your health data and samples for research purposes.

B. Sign and date the form to confirm your decision.

C. When you have completed the consent form, return it to one of the hospital secretariats or send it with a copy of a form of identity (identity card or passport) to the address indicated on the back of this document.

If you have any questions or wish to withdraw your consent, please do not hesitate to contact us:

By mail
HFR - hôpital fribourgeois
Medical Department
Case postale
1708 Fribourg

By telephone
Medical Department
T +41 26 306 01 60
Mon – Fri: 8.30 – 11.30 a.m. / 1.30 – 4.30 p.m.

By e-mail
direction.medicale@h-fr.ch

Further information (in French & German only)
www.h-fr.ch/nos-recherches/consentement-general

hôpital fribourgeois
freiburger spital

Étiquette patient

Consent form for use of health data and samples for research purposes

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Last name and first name | Date of birth

A. I agree to my health data and residual biological samples collected during my treatment (outpatient consultations and hospital stays) being retained, shared and used for research purposes.

☐ YES ☐ NO

Whatever your answer, please go to section B.

B. Confirmation of my decision

I confirm that I have been offered or have had direct contact with a medical professional to answer all my questions concerning this document, and I understand:

- the explanations on the reuse of my health data and biological samples for research purposes, detailed in the information brochure;
- that my data and samples are protected and that they will only be used for research in coded or anonymised form;
- that my data and samples may be used in national and international research projects in the public and private sectors;
- that the projects may include genetic analyses on my samples;
- that I may be contacted again in the event that results relevant to my health are identified;
- that my decision is voluntary and will not affect my medical treatment;
- that my decision is valid indefinitely unless I withdraw my consent;
- that I may withdraw my consent at any time without having to give a reason;
- that if I do not sign the consent form or if I check “NO” in section A when signing this consent, my health data and biological samples cannot be used for research.

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Place and date | Signature of the patient

Please contact us if you have any questions or comments.

By mail
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Medical Department
Case postale
1708 Fribourg

By telephone
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T +41 26 306 01 60
Mon – Fri: 8.30 – 11.30 a.m. / 1.30 – 4.30 p.m.

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Further information (in French & German only)
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