
Information on the re-use of health-related data and samples for research purposes

Dear blood donor

The detection and treatment of diseases has made enormous progress in recent decades. This development is the result of many years of research in which doctors, scientists, patients and blood donors of different generations are actively involved.

Research is largely dependent on data from blood donors. This can include, for example, results of laboratory tests, information on blood groups or genetic analysis (e.g. blood groups, iron status). Even parts of your blood donation (samples) that are no longer needed for transfusions and examination purposes are very valuable for research. These can consist of whole blood, blood plasma or platelets, for example.

This information sheet explains how you as a blood donor can contribute to medical progress and shows how your donor data and rights are protected.

We thank you for your interest and support.

How can you make your contribution to research?

If you sign the following consent form with "Yes", you are making your health-related data and residual parts of your blood donation available to research. This consent applies to all data that has already been collected by the blood donation service or will be collected in the future. This applies in the same sense to samples.

Your consent is voluntary. It is valid for an unlimited period of time unless it is revoked (withdrawn). You can revoke your consent at any time via the contact address below without giving any reason. After revocation, your data and samples will no longer be made available for new research projects. Your decision has no influence on your activity as a blood donor.

How are your health-related data and samples protected?

Your data will be processed and protected by the blood donation service in accordance with the legal regulations. Only authorised employees of the blood donation service, such as doctors, have access to the unencrypted data from your blood donation and to your unencrypted samples. Your samples are stored in biobanks. A biobank represents a structured collection of different samples under certain safety regulations (biobank regulations).

If your data and samples are used for research projects, they are encrypted or anonymised. Encrypted means that all personal data such as your name or date of birth are replaced by a code. The key, which shows which code belongs to which person, is kept safe by a person not involved in the research project. You cannot identify persons who do not have access to the key. If data and samples are made anonymous, there is no key that can be traced back to your person. For anonymized data and samples, your consent can no longer be revoked and relevant medical findings cannot be communicated to you.

Who may use your health-related data samples?

Your data and samples are made available to authorized researchers at our blood donation service for research projects or may be used in research projects in cooperation with other public or private institutions (other blood donation services, hospitals, universities or pharmaceutical companies). The projects can be carried out in Switzerland or abroad and may include genetic analyses where appropriate. In the case of research projects abroad, at least the same data protection requirements apply as in Switzerland. Research projects are generally subject to review by the competent ethics committee.

Will you be informed about research results?

Research projects involving data and samples do not generally result in information that is directly relevant to the blood donation of an individual person. However, if a result that is significant for you is found and a medical measure is available, the blood donation service can contact you. Please inform the Blood Donor Service if you wish to waive such contact and exercise the right not to be informed.

Will you have financial advantages or disadvantages?

There will be no additional costs for you. Swiss law prohibits making a financial profit with your data and samples (commercialisation ban). This applies to you and the blood donation service. In addition, the responsible ethics committee checks compliance with the legal requirements of research projects requiring authorisation.

If you have any further questions or require additional information, please use the contact address below or visit our website www.blutspende.ch

Address of the blood donation service

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

Donor Label

.....
First and last name blood donor	Date of birth

I hereby agree that my donor-related data and samples collected during my blood donation are available for research purposes.

☐ Yes ☐ No

I know, that:

- the regulations for the further use of my data, samples are described in the information sheet. I have read and understood this information.
- my personal data are protected.
- my data, samples can be used in national and international projects, within public and private institutions.
- my samples for research purposes can be used for genetic analysis.
- I can be contacted if information relevant to me is found, as long as this information is not treated in an anonymous form
- my decision is voluntary and has no influence on my treatment.
- my decision has no time limit.
- that I can withdraw my consent at any time without giving reasons, as long as the data of the samples have not been made anonymous.

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Place, Date	Signature blood donor

You will receive a copy of this page with your signature if you so wish. If you have any questions, please contact the following contact at your blood donation service:

XYZ