

Privacy statement Sanquin Research & LabServices – v10July

This privacy statement was last updated in June 2018 and overrides previous versions. Research & LabServices may amend this privacy statement from time to time. Sanquin will keep you up to date with any changes by placing a revised version of the statement on our website.

Research & LabServices - fundamental and applied research

Research & LabServices is part of the Sanquin Blood Supply Foundation. It conducts fundamental, applied and translational research in the field of blood, blood plasma medication and diagnostics. Sanquin has partnerships with (mostly academic) research centres in the Netherlands and abroad for these projects.

Sanquin is a knowledge driven organisation that delivers live-saving products and focuses on medical needs in healthcare . Through scientific research we seek to find new solutions for medical issues in the field of transfusion, haematology and immunology

Which personal data does Research& LabServices collect, how and for which purposes?

Research& LabServices processes personal data from a large number of patients and donors as well as employees and other data subjects. Examples of this data are:

- Contact details such as address, email and phone number;
- A patient or sample number;
- Personal data regarding health;
- Genetic data.

Personal data is collected in the following ways: (1) we receive personal data you provide us with when you participate in a research project; (2) we receive personal data from you when you donate blood; (3) we receive personal data from third parties such as medical institutions and doctors with whom we collaborate regarding scientific research.

Research& LabServices processes this personal data for the following purposes:

- Fundamental and applied research;
- To produce new medicines and blood products for the benefit of patients.

[Additional information - 2](#)

How does Research & LabServices ensure personal data is safe, and for how long does Research & LabServices store personal data?

Research & LabServices takes the necessary technical and organisational measures (and will continue to do so in the future) to guarantee that your personal data is well protected, for example against unauthorised or unlawful use, modification, unauthorised access or disclosure, accidental or unlawful destruction and loss.

[Additional information - 3](#)

Our policy at Research & LabServices is only to store personal data as long as it is needed. This is often to fulfil a legal obligation. For example data related to clinical trials has to be stored for 15 years after completion of the trial. Data that is no longer needed is either destroyed or anonymised.

Does Research & LabServices disclose data to third parties?

Due to the nature of Research & LabServices activities your data may be shared with third parties with whom we cooperate or maintain a partnership such as health centres, medical specialists, an METC (medical research ethical commission) and the Central Committee on Research involving Human Subjects (CCMO).

There are also institutions that monitor and test Research & LabServices' operations, such as the Health and Youth Care Inspectorate (*Inspectie voor de Gezondheidszorg en Jeugd*, IGJ). Employees at this institution can also view the data.

In certain cases, Research & LabServices may share your personal data with trusted third parties for the performance of certain technical and other services, e.g. hosting providers. All such third parties are obliged to adequately protect your data and only to process it in accordance with our instructions. Sanquin has a written contract with each of these processors, in which these matters are settled (processor agreement).

Research & LabServices may also share aggregated data, which is not traceable to a person, with third parties. Research & LabServices ensures that this non-personal information cannot be traced back to specific individuals. In addition, Research & LabServices may share your personal data with supervisory bodies and investigatory bodies if it is legally required to do so.

What are your rights?

As a data subject you have the right to access your personal data processed by Research & LabServices, to rectified inaccurate data and, in certain cases, to have your data removed.

You also have the right, in certain cases, to request a restriction of or to lodge an objection to the processing of your data and to request data portability.

To make sure that it is you requesting your data, Research & LabServices will asks you to provide a valid identity document as a proof of identity.

If you have given consent for your personal data to be used, you may revoke your consent at any time without giving a reason. From that moment on, Research & LabServices will not collect any new personal data. Research & LabServices still has the right to continue processing any of your data that was already collected before you revoked consent.

What are your rights regarding scientific research?

To facilitate scientific research a number of exceptions have been created in European and Dutch legislation with regard to the processing of personal data.

The right to access, the right to rectify and the right to restrict are not applicable for a data subject in the case of scientific research.

Contacting Research & LabServices

If you have a question, you can contact us via research@sanquin.nl.

At Sanquin, the Data Protection Officer (DPO) advises and informs on data protection, and monitors data protection compliance at Sanquin. The DPO can be reached at dpo@sanquin.nl.

If you believe that Research & LabServices does not comply with the above rules or does not do so adequately, or if you want to submit a complaint for another reason, please contact us.

Alternatively, you can submit a complaint to the Autoriteit Persoonsgegevens (AP). This is the independent Dutch supervisory body that monitors compliance with the statutory rules for the protection of personal data. You can contact the AP at:

Autoriteit Persoonsgegevens
PO box 93374
2509AJ Den Haag
Tel.: +31 (0)88 – 1805 250

Additional information - 2

At Research & LabServices, a valid reason is required in order to be allowed to process personal data. This reason is called a legal basis. The valid reasons/ legal bases which Research & LabServices has for processing data are:

- Consent;
- Performance of a contract;
- Legitimate interest of Research & LabServices or a third party.

The valid reasons, or legal bases, which we use for special personal data (such as data concerning health and genetic data) are:

- Explicit consent;
- The necessity for purposes of preventive medicine, medical diagnoses or the provision of health care or treatments;
- The necessity for reasons of general interest in the field of public health or ensuring high standards of quality and safety of health care and medicinal products;
- The necessity with regard to scientific research or statistical purposes.

If Research & LabServices processes your personal data for the purpose of the legitimate interests of Research & LabServices or those of third parties, the processing will be preceded by carefully weighing up these interests against your right to privacy. Research & LabServices takes all precautionary measures to protect your privacy and, where necessary, to prevent your interests from being conflicted. Research & LabServices can supply more information on request about how the interests are weighed up.

Research & LabServices has in relation to the following purposes a legal base for all of its processing activities.

Fundamental and applied research

Within the Blood supply organisation, Research & LabServices conducts fundamental, applied and translational (scientific) research to improve the blood supply and for medical-scientific purposes.

- (Explicit) consent;
- Performance of a contract;
- Legitimate interest of Sanquin or a third party;
- The necessity for reasons of general interest in the field of public health or ensuring high standards of quality and safety of health care and medicinal products;
- The necessity with regard to scientific research or statistical purposes.

To produce medication at the benefit of patients.

Research & LabServices produces medication of own body material at the benefit of data subjects.

- (Explicit) consent;
- The necessity for reasons of general interest in the field of public health or ensuring high standards of quality and safety of health care and medicinal products;

Additional information - 3

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Every Research & Labservices employee who has permission to access your personal data is obliged to observe secrecy. He or she must treat all of the data confidentially.

A Research & Labservices employee only has access to the data that he or she needs for the fulfilment of his or her duties. For this reason, not all Research & Labservices employees can access all personal data.

Research & Labservices has taken measures to prevent unauthorised persons from accessing your personal data. For example, Research & Labservices stores data on paper in locked rooms and electronically stored data is password protected.