

## Data protection policy

### Introduction

Data protection is a key concern for the Swiss Academy of Medical Sciences (hereinafter "**SAMS**") and the SIB Swiss Institute of Bioinformatics (hereinafter "**SIB**"). The purpose of this explanatory notice on data protection policy (hereinafter "**Policy**") is to explain the measures taken by SAMS-SIB in terms of Personal Data processing with respect to the use of the website [www.sphn.ch](http://www.sphn.ch) (hereinafter "**SPHN website**"). This Policy is intended to help You understand how We may use the data you provide as a user (hereinafter "**User**" or "**You**") of the SPHN website.

By accessing and using the SPHN website, You acknowledge that You have read, understood and accepted that You are subject to all of the conditions laid down in this Policy.

### SPHN website owner and Data Controllers

The Swiss Personalized Health Network initiative (hereinafter "**SPHN**") mandated by the Swiss federal government aims to advance research and innovation in the field of personalized medicine. The SAMS and the SIB (hereinafter the "**SAMS-SIB**" or "**We**") are responsible for carrying out the mandate related to the SPHN initiative.

#### On behalf of SAMS

Swiss Personalized Health Network (SPHN)  
 Haus der Akademien | Laupenstrasse 7  
 CH-3001 Bern  
 T +41 31 306 92 95 | [info@sphn.ch](mailto:info@sphn.ch)

The SPHN Management Office is hosted by the Swiss Academy of Medical Sciences (SAMS) and manages the overall initiative and daily operations.

#### On behalf of SIB

Personalized Health Informatics Group (PHI)  
 Elisabethenstrasse 43  
 CH-4051 Basel  
[dcc@sib.swiss](mailto:dcc@sib.swiss)

A group of SIB Swiss Institute of Bioinformatics, the PHI manages both, the SPHN Data Coordination Center and the BioMedIT project.

The SPHN website is run by SAMS. Any communication addressed to SAMS or SIB shall be in writing and will be considered valid and effective once received, if sent by ordinary post, or upon delivery of the read receipt if sent via email.

While accessing and using the SPHN website, SAMS-SIB are joint-controllers when processing Personal Data pursuant to and in accordance with the Federal Act on Data Protection (FADP) and, if applicable, the European Regulation EU 679/2016 (GDPR). Any Personal Data provided or otherwise collected while using the SPHN website will be processed in compliance with the principles laid out by the above-mentioned regulations.

### Personal data

Personal Data means any information concerning an identified or identifiable natural person. This concerns in particular information and information such as name, address or postal address, telephone number or email address, insofar as this contains an indication making it possible to identify the person. Personal Data that You communicate to the SPHN website in the registration forms, the newsletter and when making contact are used exclusively for the processing of your requests (registration, request, etc.).

## Your rights

As a User you have the following rights:

- Request that any incorrect Personal Data be corrected;
- Request, free of charge and being entitled to a written answer, whether any Personal Data concerning them are being processed;
- Request that any Personal Data Processing be interrupted or withdraw their consent;
- Request that any illegitimate Personal Data processing be interrupted;
- Request that Personal Data processing be interrupted, corrected or destroyed;
- Request that, in case there is no evidence attesting to the correctness or incorrectness of any Personal Data, a note to this effect be added to the data;
- Request that the correction, destruction, blocking, and in particular the prohibition of disclosure to third parties, the marking of the data as disputed or the court judgment be notified to third parties or published;
- Request that any collected, stored or unlawfully used Personal Data be destroyed;
- Request that a specific Personal Data processing be acknowledged as illegal;
- File a complaint in the event of failure to comply with the information, notification and cooperation obligations as well as with confidentiality obligations.

The consent given by User may be revoked with effect for future at any time by sending an email to [info@sphn.ch](mailto:info@sphn.ch). We may ask the User to provide proof of his/her identity (such as a copy of a valid ID card).

## Personal Data processing while accessing and using the SPHN website

If You only use the SPHN website for information purposes, without sharing any Personal Data, We only process Personal Data necessary for the display of the SPHN website on your device connected to the internet that You are using. These include:

- the IP address,
- the date and time of the request,
- the quantity of data transmitted,
- the type and version of the internet browser,
- the operating system used.

These log files are collected only for the sole purpose of administering the SPHN website, simplifying and improving its management and identifying and preventing unauthorized access. These log files containing the above-mentioned data shall be deleted at the latest after December 31, 2024, unless there is a legitimate interest or a service-oriented request. We reserve the right to keep server log files for longer if there is evidence to suggest illegal access (such as a hacking attempt or DDoS attack). You can request the deletion of your Personal Data by sending an email to [info@sphn.ch](mailto:info@sphn.ch).

## Email contact

When You contact us by email, the information You provide is solely used to respond to your request and to address any additional questions. These Personal Data are: courtesy form, surname and first name, street, ZIP / city, email address, telephone number, data specific to the event and / or to the funding request, message / comments. The following Personal Data is also stored when your request is sent: IP address, date and time of registration.

We use Personal Data to interact with You and to respond to your requests regarding the SPHN website or any related information to SPHN projects You might have. Personal data will be deleted no later than December 31, 2024, unless there is a legitimate interest or a service-oriented request.

## Participation in events

When You fill out the form to participate in events referenced on the SPHN website, the information You provide is used to respond to your request. These Personal Data are: first and last name, email address, postcode / city, message / comments, role, country, organization. The following Personal Data is also stored when the request is sent: the User's IP address, date and time of registration.

We use your Personal Data to interact with You and to respond to your requests regarding the SPHN website or any related information to SPHN projects You might have. Personal data will be deleted no later than December 31, 2024, unless there is a legitimate interest or a service-oriented request.

## Newsletter

When subscribing to the newsletter, first and last name, e-mail address, role, city, organization, IP address and date of registration of the person who made the request are recorded. This storage serves on one hand as proof only in the event that a third party has misused your e-mail address and has signed up to receive the newsletter without your knowledge and other hand to keep You apprised about SPHN activity, projects and events. You have, in any case, the possibility of cancelling the subscription to the newsletter, either through the link which appears in the newsletter, or by sending a message to the contact address indicated above.

## Use of cookies and Google Analytics

SPHN website uses Google Analytics, a web analysis service from Google Inc., Mountain View, CA 94043, USA. Google Analytics uses cookies (small text files), which are saved on your computer or on other devices connected to the Internet. Cookies cannot run programs or transmit viruses to your device. The site that installs the cookie may, however, obtain certain information about it. In principle, this information - including the IP address - is transmitted to a Google server in the USA and saved there. Google Analytics is configured so that IP addresses are only stored anonymously. You can find more information on data protection at:

<https://policies.google.com/privacy>.

You can refuse the use of cookies by selecting the corresponding settings on your browser. Please note, however, that this may affect your ability to use this website.

## Access to Personal Data by third-parties

Personal Data is solely handled and stored within the SAMS-SIB in Switzerland. We will not sell, nor lease, market and/or lend Personal Data to third-parties thought the SPHN website. In no event, Personal Data shall be transmitted to third-parties unless required by law or by an administrative or judicial authority.

With the exception of data disclosed to comply with legal requirements, Personal Data may also be disclosed to the following categories of third-parties:

- Web agency company that created and make the SPHN website available, besides organizing, scheduling, building and executing any task related to the SPHN website;
- IT provider for the hosting of our server.

## Security

We have implemented standard security measures (of a technical and organizational nature) in accordance with standard regulations, taking into account the risks involved in protecting information from any accidental or intentional manipulation, loss, destruction or communication, or from all non-authorized access. However, considered the status of the Internet as an "open network", We are not in a position to make any representations or warranties, nor shall it do so, that data will not be intercepted or collected by unauthorized third-parties.



### **Reservation of modifications**

This Policy may require periodic updates, including as part of the evolving regulatory framework for data protection. We invite You to check this page regularly to make sure You have read the latest version.

Last update: 30 January 2020

### **Place of jurisdiction and applicable law**

The legal relationship between You and the Website owner with regard to accessing and using the SPHN website and any resource connected to it is governed by Swiss substantive law, excluding international private law regulations. The District Court in Bern as the exclusive court jurisdiction for all controversies arising from or simply related to the use of the SPHN Website.

Effectively as of: 30 January 2020