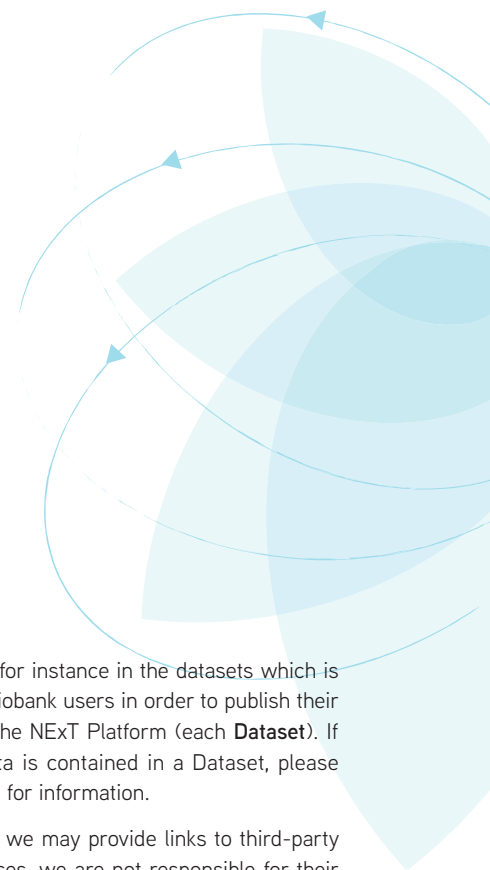


SWISS BIOBANKING PLATFORM PRIVACY NOTICE



1. INTRODUCTION

We recognize the importance of your privacy and of transparency in our processing of your personal data.

At Swiss Biobanking Platform (**we, our** or **SBP**), we recognize the importance of your privacy and of transparency in our processing of your personal data. This privacy notice (**Privacy Notice**) informs you on the personal data we collect and process in connection with the provision of our digital solutions (the **Digital Solutions**), including our website accessible at <https://swissbiobanking.ch/> (the **Website**), the Solution for Quality Assessment and Normalization (SQAN) available at <https://www.biobanksqan.ch/> (**Biobank SQAN**), as well as the NExT platform accessible at <https://ecat-biobank.sib.swiss/search> (the **NExT Platform**) and the services provided in this context (together with the provision of the Solutions, our **Services**).

By accessing and using our Services, you expressly acknowledge that we may collect and process your personal data in accordance with this Privacy Notice.

This Privacy Notice is incorporated into and forms an integral part of our terms of use for the Swiss Biobanking Platform (**ToU**). All capitalized terms not defined in this document have the meaning given to them in the ToU.

2. WHO IS RESPONSIBLE FOR THE PROCESSING OF YOUR PERSONAL DATA

Swiss Biobanking Platform, Route de la Corniche 3A, Bâtiment Phényl, 1066 Epalinges, Switzerland, is responsible for the processing, as controller, of your personal data. You will find our contact details below in Section 12.

This Privacy Notice only applies to processing undertaken by or on behalf of us as data controller. Except for section 14 of this Privacy Notice, it does not apply when we process the personal data of individuals who are not users of the the Solutions provided to us by

one of our users, for instance in the datasets which is provided by our Biobank users in order to publish their E-Catalogues on the NExT Platform (each **Dataset**). If your personal data is contained in a Dataset, please refer to section 14 for information.

In addition, whilst we may provide links to third-party websites or services, we are not responsible for their policies in relation to personal data. In such circumstances, the collection and use of your personal data are governed by the privacy policy of those third-party websites or services, which you should carefully review to learn more about their personal data processing practices.

3. SHORT VERSION

The following is a brief summary of (but not a replacement for) this Privacy Notice:

- As part of our operation of the Services, we may collect personal data which is provided to us by you or your organization (see section 4);
- We process such personal data in compliance with Swiss laws and other laws applicable to us, mainly for the purpose of operating the Solutions and providing our related Services (in particular to conduct quality assessment of Biobanks and to enable Biobanks and researchers to communicate and interact). We may also process your personal data to communicate with you, send our newsletter, analyze and improve the use of our Services and to comply with our legal obligations (see section 7, as well as sections 5 and 6);
- In connection with our NExT Platform, we may also process personal data of individuals which is contained in the datasets sent to us by Biobanks in order to publish their E-Catalogues. In this case, we process such data as data processor, in accordance with the contract between us and the Biobank which is the data controller of such data. This Privacy Notice does not address how your organization collects and uses your personal data or how we process your data when we act as processor for your organization. You must refer to your organization's privacy policy for information about its

- processing activities (see section 14);
- Your personal data is stored in Switzerland. We do not share it with third parties or transfer it abroad unless this is both necessary for the operation of the Services and permitted by Swiss laws. This may for instance be the case when we use service providers or must interact with third parties to conduct our professional activities. However, some information on the Solutions is available publicly or to other users, and thus world-wide (see sections 8 and 9);
 - We apply security measures and strive to protect your personal data. However, no IT infrastructure is completely secure and we cannot guarantee that ours will (see section 11);
 - You may contact us info@swissbiobanking.ch to exercise your rights pertaining to your personal data (see sections 13 and 15).

4. HOW WE COLLECT YOUR PERSONAL DATA

We collect the personal data that you or other users provide to us.

We collect the personal data that you or other users provide to us when using our Services, for example when you create and/or manage your account, you use our Solutions, communicate with us or other users, through web forms you fill, or when you subscribe to our newsletter.

If your personal data is contained in a Datasets uploaded by one of our Biobank users in connection with our NEXt Platform, please refer to section 14.

Some information is mandatory and some is optional.

It is mandatory that you complete the data fields identified by an asterisk. If one or more mandatory data fields are not completed, we will not be able to provide access to our Services. You are not required to complete the optional data fields in order to access our Services. If you have an account, these fields may be completed at any time through your account settings.

Certain personal data are also collected in an automated manner.

We also automatically collect personal data, including by means of tools, web forms, cookies and other active elements, as further described in this Privacy Notice.

You may define certain authorizations relating to the automatic collection of your personal data when you configure your device or your internet browser according to available functionalities. You may also define certain settings for the automated collection of your personal data through the cookies setting plugin available on each Solution. For more detailed information, please see the cookie section below (section 12).

5. HOW WE PROCESS YOUR PERSONAL DATA

We process your personal data for the purposes indicated in this Privacy Notice and in accordance with applicable law, including by automated means.

We process your personal data in compliance with applicable law, in particular Swiss data protection law and, to the extent they apply to us, other data protection legislations, such as the EU General Data Protection Regulation (GDPR) or its equivalent in the United Kingdom, and may use in this context computers or computer tools, in line with the purposes set out in this Privacy Notice.

We do not process your personal data to create a profile about you (profiling). We also do not make decisions exclusively on the basis of an automated processing which have legal effects on the data subjects or affect them significantly (automated individual decision).

We take the technical and organizational appropriate security measures to prevent unauthorized access, disclosure, modification, alteration or destruction of your personal data, as specified in Section 11 below.

6. ON WHICH LEGAL GROUND DO WE PROCESS YOUR PERSONAL DATA

We process your personal data only if we have a valid legal ground to do so.

We will only process your personal data if we have a valid legal ground for doing so. Depending on the processing activity carried out, we will therefore only process your personal data if:

- The processing is necessary to fulfill our contractual obligations to you or to take pre-contractual steps at your request (**Contractual Necessity**);

This is the case in particular when processing your personal data is strictly required to provide you with the Services, as further specified in section 7 below. When the GDPR applies, Contractual Necessity is based on Article 6(1)(b) GDPR;

- The processing is necessary for the fulfillment of our legitimate interests, and only to the extent that your interests or fundamental rights and freedoms do not require us to refrain from processing (**Legitimate Interest**);

Our Legitimate Interests include in particular (i) ensuring that our Services are provided in an efficient and secure way (e.g. through internal analysis of the Services' stability and security, updates and troubleshooting, as well as support services); (ii) improving and developing the Services (including monitoring the use of our Services, and for statistical purposes); (iii) benefiting from cost-effective services (e.g. we may opt to use certain services offered by suppliers rather than undertaking the activity ourselves); and (iv) achieving our corporate goals. When the GDPR applies, Legitimate Interest is based on Article 6(1)(f) GDPR;

- We have obtained your prior consent in a clear and unambiguous manner (**Consent**);

When the GDPR applies, Consent is based on Article 6(1)(a) GDPR;

- The processing is necessary to comply with our legal or regulatory obligations (Legal Obligation);

Finally, we will process your personal data if we are required by law to do so, as further specified in section 7 below. When the GDPR applies, Legal Obligation is based on Article 6(1)(c) GDPR.

7. PURPOSES FOR WHICH WE PROCESS YOUR PERSONAL DATA?

We process your personal data for legitimate and clearly identified purposes:

Your personal data is collected and processed for the purpose of operating the Services and for the other legitimate purposes explicitly specified below, only to the extent relevant to achieve these purposes, and is not further processed in a manner that is incompatible with them.

We process your personal data for the following purposes:

To operate the Solutions and provide the related Services.

We mainly process your personal data to operate the Solutions and provide the Services, including for

creating and maintaining a user account, interacting with you and other users (including for allowing users of the Solutions to query the databases and communicate between them), making certain information about participating Biobanks available online, providing you with the requested information and Services, as well as for user management purposes. If you are a user of the Services, we do based on our Contractual Necessity to provide you with the requested Services, and if you are not, based on our Legitimate Interests in providing such Services to our users.

In addition to the personal data which you provide when logging-in to your account or interacting with the Solutions (e.g. when you fill in forms or upload content to the Solutions), we automatically collect technical information about your interactions with the Solutions, such as IP address, the content that was accessed, date and time of access, information about your web browser, your preferences, or other information related to your interaction with the Solutions, including your navigation details on the Solutions. We process this data [to establish a connection with your device over the internet, to identify you when you use the Solutions, control the use of the Solutions and manage their stability and security, based on our Legitimate Interest to do so.

Your account information is retained for as long as your account is active. If you suppress your user account, your account information will be deleted or anonymized within 30 days after such event, unless data must be retained for a valid reason (such as evidentiary or tax purposes). Log files are automatically deleted or anonymized 30 days after their collection, unless we must retain them for a valid reason.

To contact you and respond to your queries.

You have the option of contacting us by email or by using the dedicated communication tool implemented in the Solutions. In this context, we process the data which you provide to us (including your contact information and the subject matter of the request). This data is used for the purpose of providing you with the requested information and services, based on our Contractual Necessity. The retention period depends on the reason for your request and its context.

To send you our newsletter and other advertising information.

If you subscribe to our newsletter, we will collect your contact details (name and email address) and use it to provide you with our newsletter, based on your Consent. You may unsubscribe from the newsletter service at any time, in which case your contact details will be deleted.

We also process the time of registration and your opt-in confirmation based on our Legal Obligation to

demonstrate compliance and analyze your use of our newsletter (e.g. whether you have opened it or clicked on certain links) and process this data to optimize and improve our newsletter, based on our Legitimate Interest.

We use the third party services of Mailchimp to provide our newsletter service. MailChimp will have access to your login data in order to provide you with the service. Its privacy statement is applicable in connection with this, which you will find here: <https://mailchimp.com/legal/privacy>.

Independently from your subscription to our newsletter, we may also contact you by email to inform you about our activities if you are a registered user of one of our Services and have not objected to the corresponding use of your email address. You can object to the use of your email address for this purpose at any time by contacting us (see contact detail in section 15). The legal basis for the corresponding processing of your data is our Legitimate Interest to advertise certain activities relating to our previous interactions with you.

For internal analysis and statistical purposes in order to improve our Services.

Unless you object to such processing, we may process your personal data relating to your interactions with the Services (e.g. the content you accessed, date and time of access and your preferences), for internal analysis and statistical purposes, in order to better understand the needs of our users, to optimize their experience, and in general to improve the ergonomics and functionality of our Services. You may object to such processing activities at any time (see section 13 below for additional information on your rights).

We do not link this information to you or your account. We use analytics tools provided by known market providers – such as Google Analytics – which provide to us only aggregated, non-identifiable data. The privacy policy of those service providers is applicable in this context, which you will find in section 12.

You will find additional information in section 12 in relation to the use of cookies for this purpose, including on the duration for which data collected this way are stored. Data collected by other means and delete or anonymized it at the latest 30 days after its collection.

To comply with our other Legal Obligations or for other Legitimate Interests.

We may further process your personal data if we have a Legal Obligation to do so or for other Legitimate Interests. This will for instance be the case if we need to disclose certain information to public authorities or retain such information for tax or accounting purposes, or for the establishment, exercise or defense of legal claims.

The personal data that we process for this purpose are those that we collected for one of the purposes indicated elsewhere in this section 7. We retain the personal data for the duration of the legal obligation imposed on us.

If we have obtained your consent.

In addition to the above, we may process your personal data if we have obtained your prior unambiguous consent for specific purposes. Consent given can be withdrawn at any time, but this does not affect data processed prior to withdrawal.

8. THE CIRCUMSTANCES IN WHICH WE DISCLOSE YOUR PERSONAL DATA TO THIRD PARTIES

We may disclose your personal data to third parties if this is necessary for the operation of our Services, if there is a legal obligation or permission to do so, or if there is another valid reason to do so.

We may disclose your personal data to third parties in connection with the operation of the Services and to subcontractors such as IT service providers, and consultants. In particular, we use the services of the SIB Swiss Institute of Bioinformatics, which is based in Switzerland, to store the Datasets and the personal of our users.

With the consent of the Biobanks, we also share certain limited information with the BBMRI Directory, which may include the names of their users.

Some information is accessible to other users or the public

Your personal data may also be made available to other users of the Services or to third parties to the extent necessary for the proper operation and provision of the Services, for example for the purpose of enabling users to interact with or to query the SQAN database or the E-Catalogues of Biobanks.

We may also disclose your personal data to third parties where we have a legal obligation to do so or a legitimate interest in doing so.

We may also disclose your personal data where we have a legitimate interest in doing so, for example (i) to respond to a request from a judicial authority or in accordance with a legal obligation; (ii) to bring or defend against a claim or lawsuit; or (iii) in the context of restructuring, in particular if we transfer our assets to another entity.

9. INTERNATIONAL TRANSFERS

Your personal data is stored in Switzerland, but may in limited certain circumstances be disclosed in other countries.

We store your personal data on servers located in Switzerland.

In principle, we do not transfer your personal data to other countries or make it available there. However, in certain circumstances, in particular in connection with the operations of our subcontractors, your personal data may be made available to recipients located abroad (e.g. we use the services of MailChimp to send our newsletter, which is headquartered in the U.S. and from where some data may be available). In such cases, we will ensure that suitable safeguards are in place, in accordance with applicable data protection laws, for instance by relying on standard contractual clauses adopted by the European Commission.

Moreover, the information accessible to the public or to other users on the Solutions may be accessed worldwide. Finally, as indicating above, we may share certain limited information with the BBMRI Directory with the consent of the relevant Biobanks.

If you transmit information and data to us, you are expressly deemed to consent to such data transfers. You may request additional information in this regard and obtain a copy of the relevant safeguards upon request by sending a request to the contact address indicated in section 15 below.

10. HOW LONG WE STORE YOUR PERSONAL DATA?

Your personal data will not be stored longer than necessary.

We will erase or anonymize personal data as soon as it is no longer necessary for us to fulfill the purposes set out in section 7 of this Privacy Notice. This period varies, depending on the type of data concerned and the applicable legal requirements. More information on each type of processing can be found in section 7 above. If you suppress your user account, we will delete your personal data and all user content associated with it within 30 days after such event, unless data must be retained for another user from your organization or for another valid reason.

11. SECURITY

We maintain physical, technical and procedural safeguards to keep secure your personal data.

We are committed to the security of your personal data, and have in place physical, administrative and technical measures designed to keep secure your personal data and to prevent unauthorized access to it. We restrict access to your personal data to those persons who need to know it for the purpose described in this Privacy Notice. In addition, we use standard security protocols and mechanisms to exchange the transmission of sensitive data. When you enter sensitive information on our Solutions, we encrypt it using Transport Layer Security (TLS) technology.

Although we take appropriate steps to protect your personal data, no IT infrastructure is completely secure. Therefore, we cannot guarantee that data you provide to us is safe and protected from all unauthorized third-party access and theft. We waive any liability in this respect.

The internet is a global environment. As a result, by sending information to us electronically, such data may be transferred internationally over the internet depending upon your location. Internet is not a secure environment and this Privacy Notice applies to our use of your personal data once it is under our control only. Given the inherent nature of the internet, all internet transmissions are done at your own risk.

If we have reasonable reasons to believe that your personal data have been acquired by an unauthorized person, and applicable law requires notification, we will promptly notify you of the breach by email (if we have it) and/or by any other channel of communication (including by posting a notice on the Solutions).

12. HOW WE USE COOKIES OR OTHER ANALYTICAL TOOLS

We use Cookies, other analytical tools and similar technologies in connection with the Next Platform.

We use various types of cookies, other analytical tools or similar technologies (collectively, Cookies) in connection with the Solutions, some of which are capable of automatically processing data on your electronic device and/or of transferring personal data about you to us or third parties.

These technologies are generally used to monitor and analyze your interactions with the Solutions and/or to enable us to improve the Solutions and their functionalities, including customizing the Solutions and related services, depending on your interactions. We may also use Cookies to measure and monitor the traffic and use of the Solutions and their performance.

Cookies are generally divided in four categories:

A. Essential Cookies. Some cookies are placed on your electronic devices to make the Solutions capable

of being used, by providing basic features such as page browsing and accessing secure areas. The Solutions rm cannot function properly without this type of Cookies.

B. Functionality Cookies. Some Cookies enable the Solutions to remember choices persons make, for example, user name, and language or text size. These cookies are known as “functionality cookies” and help to improve a person’s experience of the Solutions by providing a more personalized service.

C. Advertising Cookies. These cookies are used to better understand user interests and to display more relevant advertisements.

D. Analytics/productivity Cookies. Analytics/productivity Cookies, such as those linked to Google Analytics, help understand how users interact with the Solutions by anonymously collecting and reporting information.

Our use of cookies may vary depending on which Solution you use. You will find the list of cookies we use, as well as links to the applicable privacy policy of their providers, on the cookie management interface of the Solution you use, which is available here.

You can manage Cookies through the settings of your web browser and/or electronic device, as well as through the interface available on the Solution you use.

If you do not want Cookies to be stored on your electronic device, you can configure your internet browser or electronic device to refuse and/or restrict them. You may also set the use of Cookies on the Cookie management page of the Solution you use. However, some Cookies are essential to the functioning of the Solution, and it may operate differently if you refuse or completely restrict Cookies.

For more information, please visit the website <http://www.allaboutcookies.org>. You can also see the help section of your internet browser or electronic device for more specific instructions on how to manage Cookies.

13. YOUR RIGHTS WITH REGARD TO THE PROCESSING OF YOUR PERSONAL DATA

You have the right to access your personal data we process and may request without limitation that they be removed, updated, or rectified.

Unless otherwise provided by law, you have the right to know whether we are processing your personal data. You may contact us to know the content of such personal data, to verify its accuracy, and to the extent permitted by law, to request that it be supplemented,

updated, rectified or erased. You also have the right to ask us to cease any specific processing of personal data that may have been obtained or processed in breach of applicable law, and you have the right to object to any processing of personal data for legitimate reasons. However, if you are not User, you should direct your privacy inquiries relating to the use of your personal data, including any requests to exercise your data protection rights, directly to the user which has provided us with such information (see section 14).

By accessing your user account (if you have one), you can review, update, correct or delete the personal data available within your user account.

If you request us to delete your personal data from our systems, we will do so unless we need to retain your data for legal or other legitimate reasons. Please note that any information that we have copied may remain in back-up storage for some period of time after your deletion request.

Where we rely on your consent to process your personal data, we will seek your freely given and specific consent by providing you with informed and unambiguous indications relating to your personal data. You may revoke at any time such consent (without such withdrawal affecting the lawfulness of processing made prior to).

The above does not restrict any other rights you might have pursuant to applicable data protection legislation under certain circumstances. In particular, if the GDPR applies to the processing of your personal data the GDPR grants you certain rights as a data subject if the respective requirements are met:

- **Right of access** (Art. 15 GDPR) - you have the right to access and ask us for copies of your personal data.
- **Right to rectification** (Art. 16 GDPR) - you have the right to ask us to rectify personal data you think is inaccurate. You also have the right to ask us to complete information you think is incomplete.
- **Right to erasure** (Art. 17 GDPR) - you have the right to ask us to erase your personal data in certain circumstances.
- **Right to restriction of processing** (Art. 18 GDPR) - you have the right to ask us to restrict the processing of your personal data in certain circumstances.
- **Right to data portability** (Art. 20 GDPR) - you have the right to ask that we transfer in a structured, commonly used and machine-readable format the personal data you gave us to another organization, or to you, in certain circumstances.
- **Right to object to processing** (Art. 21 GDPR) - you have the right to object to the processing of your personal data which is based on our Legitimate Interests, in certain circumstances. In such case, we will no longer process the personal data unless we demonstrate

compelling legitimate grounds for the processing, which override your interests, rights and freedoms or where the processing is necessary for the establishment, exercise or defense of legal claims.

As a rule, you are not required to pay any charge for exercising your rights and we will respond to your request within one month.

You will find further details of your rights in sections 5 and 7 of this Privacy Notice in connection with each processing activity we perform. If you want to exercise any of your rights, or want additional information about them, please contact us using the contact detailed listed below (see section 15).

You have the right to lodge a complaint with the competent authority.

If you are not satisfied with the way in which we process your personal data, you may lodge a complaint with the competent data protection supervisory authority, in particular in the Member State of your habitual residence, place of work or place of the alleged infringement, in addition to the rights described above.

Although this is not required, we recommend that you contact us first, as we might be able to respond to your request directly.

14. PROCESSING OF PERSONAL DATA CONTAINED IN DATASETS

This section 14 applies when we collect personal data about individuals contained in the Datasets which are provided to us by our Biobank users in order to publish their E-Catalogues on the NEXt Platform.

If you consider that your personal data may be included in a Dataset of a Biobank, please read the following:

- In such situation, we process your personal data as data processor, in accordance with the contract between us and the Biobank which is the data controller of such data, in accordance with its written instructions as stated in our Terms of Use. It is the Biobank which is responsible for ensuring that your personal data is collected and transferred to us in accordance with all privacy and data protection laws of all relevant jurisdictions, based on an appropriate legal ground. This Privacy Notice does not address how your organization collects and uses your personal data or how we process your personal data when we act as processor for your organization (except for this section 14, and sections 8,

9, 11 and 16). You must refer to the Biobank's privacy policy for information about its processing activities.

- The information which is contained in the Datasets may contain sensitive personal data about you, in particular health data (such as information relating to diseases, and so on). However, the information that we receive in this context is pseudonymized (which means that the pieces of information that could directly identify you, such as your name and your address, is either replaced by a random code or not provided to us at all). For this reason, we cannot link the information we receive to you (and we will not attempt to).
- If you would like to make any requests or queries regarding your personal data, please contact such Biobank directly. For example, if you wish to request to access, correct, amend, or delete inaccurate personal data contained in a Dataset, please direct your query to the relevant Biobank. As stated above, because we only receive pseudonymized data, we cannot link the information stored in a Dataset with you; only the Biobank can. If we are requested by a Biobank to amend or remove any personal data contained in a Dataset, we will respond to such request in a timely manner in accordance with applicable law (as a rule within 30 days).

15. CONTACT US

If you believe your personal data has been used in a way that is not consistent with this Privacy Notice, or if you have any questions or queries regarding the collection or processing of your personal data, please contact us at info@swissbiobanking.ch.

16. UPDATES TO THIS PRIVACY NOTICE

This Privacy Notice may be subject to amendments. Any changes or additions to the processing of personal data as described in this Privacy Notice affecting you will be communicated to you through an appropriate channel, depending on how we normally communicate with you (including by email and/or via the Services, e.g. banners, pop-ups or other notification mechanisms). If you do not agree to the changes made, you must stop accessing and/or using the impacted Services.

Last updated: 13.07.2021