



# International Society for Clinical Biostatistics

## GDPR Policy

Last updated: 31 January 2020

### Personal Data Protection Statement of the International Society for Clinical Biostatistics

The International Society for Clinical Biostatistics (hereinafter referred to as THE SOCIETY), recognises and respects the importance of the personal data it handles within the framework of its activities and therefore has adapted its policy to the requirements of the General Data Protection Regulation (hereinafter GDPR) 2016/679/EC.

By this statement, the SOCIETY wishes to inform anyone contacting it in any of the following ways:

- by phone
- on its official e-mail addresses **office@iscb.info** and **secretariat@iscb.info** or through its website
- using any of its services

in what capacity, for what purpose and on what legal basis it processes information relating thereto and which can be used to identify them directly or indirectly, namely:

- their personal data,
- the categories of their data,
- the sources of their data (when data are not provided by the person themselves),
- the criteria for determining the period of keeping their personal data,
- their option to exercise with respect to their personal data the rights to access and rectification and, where appropriate, to erasure, restriction and objection to the processing as well as to automated decision-making, including profiling, any per chance transfer of data to third countries or international organisations,
- the option of individuals to denounce any violation of their personal data rights to the Data Protection Authority as well as the observance of the relevant data protection policies and guarantees of personal data protection by the SOCIETY.

To this purpose, please take a few minutes to read the SOCIETY statement.

If you have any questions or concerns, if you wish to receive a copy of this statement or if you wish to exercise any of the rights related to your personal data, you can contact us by email at **office@iscb.info**.



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## SOCIETY STATEMENT

### 1. The SOCIETY as "Controller" and "Processor" of Personal Data

The International Society for Clinical Biostatistics was founded in 1982 and as of June 2018 is an association of articles 60 et. sec. of the Swiss Civil Code, registered in the Business Directory of the Canton of Geneva (REG) under number CHE-335.703.049. It has its registered office in Geneva, Switzerland, Chemin du Petit-Bel-Air 115, CH-1226 Thonex and it is managed by an Executive Committee, comprising of four (4) Officers and around ten (10) Ordinary Members.

The SOCIETY processes, in the course of its activity, the personal data of the parties trading with it, becoming as regards such data the "controller" or "processor".

In carrying out its aims and scopes listed in its constitution, the SOCIETY processes (simple and special category) personal data of the subjects participating in the Programs for the purposes of implementation, evaluation and control and the relevant legal obligation for the processing of personal data in the form of individual participants' data (microdata) derives mainly from both the General Regulation and the European Social Fund Regulation as well as from specific provisions of the national legislation.

The data processing concerned is governed by the provisions of Regulation 2016/679 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data and repealing Directive 95/46/EC (General Data Protection Regulation).

### 2. Data sources

The SOCIETY collects your personal data from various sources. Particularly:

- 1) Personal data you directly provide to it;
- 2) Personal data that it collects automatically. The following may be collected:
  - Your IP address;
  - Your cookie ID;
  - Your browser;
  - Your location;
  - The web pages you visit on our website ([www.iscb.info](http://www.iscb.info));

as well as

- 3) Personal data collected from other sources, i.e. from other public authorities as well as from publicly accessible sources.
- 4) Personal data collected from its contacts with companies / sponsors of its Programs

### 3. Categories of data

The data we process, as the case may be, are:

- Simple Data, such as mainly first and last name, date of birth, ID number, Transaction Identification Number), address, telephone, e-mail, etc.
- Special Category data, such as data on religion, nutritional allergies, possible health problems and data on ethnic origin.



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## 4. Purpose of Processing

The reasons the SOCIETY processes your data, as the case may be, are:

- to communicate with you;
- to answer your questions;
- to process your requests;
- to conclude contracts with you;
- to execute its contractual obligations towards you;
- to declare your membership status and any related entitlement;
- to declare your participation in events / activities;
- to fulfil its legal obligations under the national and EU law;
- to organise its activity in the field of electronic communications; and finally,

## 5. Legal bases of processing

In particular, as the case may be, the legal bases on which we support the processing of your data are the following:

- **Article 6, par. 1a of GDPR**  
When you have given consent to the processing of your data for one or more specific purposes.
- **Article 6, par. 1b of GDPR**  
Processing necessary for the performance of a contract to which you are a party or in order to take steps at your request prior to entering into a contract.
- **Article 6, par. 1c of GDPR**  
Processing necessary for our compliance with our legal obligation as this derives from the EU or the National Law.
- **Article 6, par. 1e of GDPR**  
Processing necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the Controller.
- **Article 6, par. 1f of GDPR**  
Processing necessary for the purposes of the legitimate interests pursued by the SOCIETY, except where such interests are overridden by your interests and fundamental rights and freedoms as data subjects.

And with regard to special category data:

- **Article 9, par. 2a of GDPR**  
When you have given consent to the processing of your special category data (nutritional specificity, health, ethnic origin) for one or more specific purposes.
- **Article 9, par. 2b GDPR**  
Where processing is necessary for carrying out the obligations and exercising specific rights of data subjects in the field of social protection, in so far as it is authorized by the Union or national law.



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And as regards data relating to criminal convictions and offences:

- **Article 10 of GDPR**

Where processing is authorized or required by the Union or national law.

## 6. Disclosure to third parties

The SOCIETY does not proceed to any unauthorised disclosure or transfer of your personal data to third parties. Therefore, it will not share your data with third parties for marketing purposes.

It uses processors, i.e. third parties, providing services thereto. It has contractually bound the processors in order not to be able to manage your personal data unless it gives them specific instructions and thus they will not share your personal data with anyone other than the SOCIETY itself, while it will retain your data safe for the period that it has indicated to you.

In some cases, it may have a legal obligation to disclose your data. Such a case occurs on the basis of a court order or when it cooperates with other public authorities and bodies within the European Union, under provisions of the EU or domestic law.

The SOCIETY may, therefore, disclose or transfer your data to third parties, provided the legal requirements are met, namely when there is:

- Previous consent on your behalf as data subjects;
- Legal Obligation to disclose data to Competent State Agencies and Organizations and to the relevant Judicial and Prosecution Authorities, if lawfully and competently requested.

## 7. Retention Period of your Data

The SOCIETY shall retain your personal data for as long as the processing purpose lasts. Upon its expiration, the SOCIETY shall lawfully retain your personal data when this is necessary in order to comply with a legal obligation thereof arising from the provisions of the Union or National Law and where retention is necessary to substantiate, exercise or support legal claims of the SOCIETY.

## 8. Which are your rights

According to the General Data Protection Regulation, depending on the legal basis on which SOCIETY is based to process your data, you have the following rights:

### 8.1 Right of Access

You have the right to receive:

- confirmation as to whether or not your personal data are being processed and
- a copy of such data

You may submit your request to access your personal data in writing, by email to the SOCIETY.

You may not want all the personal data that the SOCIETY has on you. For this reason, it would facilitate and speed up the process if you clarified to the SOCIETY precisely which data you want.



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## **When can the SOCIETY refuse to grant access?**

The SOCIETY may refuse to satisfy the right of access if your data include other person's personal data unless the other person has consented to the disclosure of his or her data or it is reasonable that the said information is provided to you without the consent of the other person.

In order to make the relevant decision, the SOCIETY will need to regulate your own right of access vis-a-vis the other person's rights with respect to his or her own information.

The SOCIETY shall also be entitled to refuse to grant access when this is clearly unfounded or abusive.

In any case, the SOCIETY should notify you and justify its decision. It should also inform you of your right to make a complaint to the Geneva Data Protection Authority or even to appeal before Geneva Courts.

## **How long will it take for the SOCIETY to respond?**

The SOCIETY must answer your request within a month.

In specific cases, extra time may be needed to assess your request and up to two months to answer.

If it is going to use the additional time, the SOCIETY will inform you within one month of the reason why it needs more time.

## **Can the SOCIETY charge a fee for satisfying my right of access?**

A copy of your personal data will be provided to you free of charge. However, if your claim is manifestly abusively repeated or excessive, it may charge you a fee for the administrative costs associated with it.

## **8.2 Right to Rectification**

You have the right to ask for your data to be rectified when they are inaccurate or completed when they are incomplete.

In order to exercise your right, you must inform the SOCIETY that you dispute the accuracy and completeness of your personal data. You will need to identify what data are inaccurate or incomplete, explain how the SOCIETY will have to correct them and provide relevant evidence of inaccuracies.

When you ask the SOCIETY to rectify your data, it will thoroughly check whether the data are accurate or not, on the basis of the evidence you will provide thereto and those held by it. It will then let you know if it has rectified, erased or completed the data. In case the SOCIETY considers that the inaccuracy or incompleteness of the data is not substantiated, it will inform you accordingly, providing at the same time a justification for its negative response. If it has disclosed the data to third parties, the SOCIETY will contact them and inform them of the rectification or completion of the data, unless this is impracticable or requires disproportionate efforts. At the same time, if you wish, it can inform you to which recipients it has transferred your data.

## **8.3 Right to Erasure**

You have the right to request the erasure of your personal data if you no longer wish to have such data processed and if there is no legitimate reason for the SOCIETY to hold them as Controller.

In particular, this right shall be exercised:

- when the legal basis of processing is your consent and you withdraw it, so, if there is no other legal ground for the processing, data must be erased;
- where your data are no longer necessary in relation to the purposes for which they were collected or otherwise processed or illegally processed or if you object to the processing thereof and there are no overriding legitimate grounds for the processing; and, finally,



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- if the data have been collected illegally or when you were a child within the frameworks of provision of an on-line service.

It should be noted, however, that this is not an absolute right, as further retention of personal data by the SOCIETY is lawful when it is necessary for reasons such as compliance with a legal obligation of the SOCIETY or the establishment, exercise or defence of legal claims.

The SOCIETY is entitled to refuse to erase the data in the following cases:

- when retention of data is necessary for exercising the right of freedom of expression and information;
- when retention of your data is a legal obligation;
- when retention of your data is necessary for reasons of public health;
- when retention of your data is necessary for the establishment, exercise or defence of legal claims;
- when erasing your data would significantly hinder or render processing impossible for scientific or historical research purposes.

## 8.4 Right to Restriction of Processing

As an alternative to the right to erasure and the right to object, you have the right to request the restriction of your data processing only where one of the following applies:

- the accuracy of your data is contested by you and the SOCIETY as Controller considers the request;
- when processing is unlawful;
- when data are no longer necessary for the purpose of the processing, but you are requesting their retention for the establishment and defence of your legal claims;
- when you have objected to processing and the SOCIETY as Controller examines whether the legitimate grounds thereof override yours.

This right may be combined with the right of rectification and the right to object, and in particular:

1. If you request correction of your inaccurate data, you may request that the processing be restricted for as long as the SOCIETY examines the request for rectification or
2. If you request the right to object, you may request at the same time the restriction of processing for as long as the SOCIETY examines the request to object.

## 8.5 Right to Data Portability

You have the right to receive your personal data that have been processed by the SOCIETY as controller in a structured, commonly used and machine-readable format (e.g. XML, JSON, CSV etc.).

You also have the right to ask the SOCIETY to transmit those data without hindrance directly to another Controller.

The right to portability can only be exercised by you when the following conditions are cumulatively satisfied:

- Personal data are processed by automated means (i.e. printed records are excluded);
- The processing is based either on your consent or on the performance of a contract to which you are a party (Article 6 par. 1b of GDPR);
- Personal data concern you as data subject and have been provided by you;
- The exercise of the right does not adversely affect the rights and freedoms of others.



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## 8.6 Right to object

You have the right to object at any time and on grounds related to your particular situation to processing of personal data concerning you when processing is based either on a task carried out in the public interest or on the existence of a legitimate interest pursued by the company, including profiling.

The SOCIETY shall no longer process the personal data unless it demonstrates compelling legitimate grounds for the processing which override your interests, rights and freedoms as data subject or for the establishment, exercise or defence of legal claims.

## 8.7 Right to Non-Automated Individual Decision-Making including Profiling

If the SOCIETY is required to make a decision that produces legal effects concerning you based solely on automated processing, including profiling, we inform you of the following:

- The SOCIETY as controller may lawfully take such a decision only if you have given us your explicit consent or when the decision is necessary for entering into or performance of a contract between us or if such a decision is authorized by the Union or National law, which also lays down suitable measures to safeguard the data subject's rights.
- If such a decision is taken as necessary for entering into or performance of a contract between us, namely the SOCIETY as the Controller and you as the data subject or based on your explicit consent, you have the right to contest the decision so that the SOCIETY will be obliged to implement suitable measures to safeguard your rights, at least the right to obtain human intervention in decision-making, or the right to express your point of view and contest the decision as data subject.
- If the SOCIETY intends to process data automatically, including profiling, it will provide you, when receiving the data (when it has collected them from you) or in a reasonable time (when such data have been taken from another source), also the following additional information:
  - whether and to what extent automated decision-making, including profiling, takes place;
  - on the logic involved;
  - on the importance and the foreseeable consequences of the processing;
  - information on the subject's right to object, which is presented clearly and separately from any other information.

You are entitled, in the case that profiling takes place, to obtain restriction of processing at any stage thereof.

The SOCIETY will be obliged to erase the relevant personal data if profiling is based on your consent and this is revoked or if you exercise the right to erase your data and if there is no other legal basis for processing in accordance with the provisions of Regulation.

You have the right to object at any time and on grounds related to your particular situation to processing of personal data concerning you when processing is based on the existence of a legitimate interest pursued by the company, including profiling and the SOCIETY shall no longer process the personal data unless it demonstrates compelling legitimate grounds for the processing which override your interests, rights and freedoms as data subject or for the establishment, exercise or defence of legal claims.

## 9. Security of Personal Data

The SOCIETY implements appropriate technical and organizational measures to ensure an adequate level of protection of personal data in order to prevent the destruction, loss, alteration, unauthorized access, disclosure or transfer to a non-entitled person or entity in any way.



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The SOCIETY will have business continuity and recovery plans, which it will periodically test and update; it is herein establishing and implementing appropriate policies and procedures for the security and protection of the data it processes.

In addition, to that purpose, the SOCIETY has reviewed the contracts it holds with the processors to commit them to respect your personal data under the GDPR by taking and enforcing measures to secure them from risks of destruction, loss, alteration unauthorized access, disclosure or transfer to a non-entitled person or entity, in any way and by signing a confidentiality clause.

## **10. Links to other websites**

When we provide links to websites or other Organisations, this personal data protection notice does not cover the way in which these sites or Organisations process your personal data and the information provided by you in general. That is why we encourage you to read the privacy policies of other websites you visit.

## **11. Social Media**

The SOCIETY may maintain social media accounts for members' information, as well as announcements related with its activities. The SOCIETY does not share your data with other organisations, but social media authorities may have access to visitors' data. For this reason, please read the Privacy Policy of the respective providers and companies.

## **12. Revision of the Personal Data Protection Statement**

This statement is subject to periodic revisions and updates. In this case you will be informed through the SOCIETY's website.