

Social Genomics Privacy Statement

We are passionate about saving lives by sharing knowledge. We are also passionate about privacy.

You're in control of your data.

It is important to us that we are diligent when it comes to your privacy. That's why we have built our services with user privacy at the centre of everything we do - and given you the tools to control your data.

At SocialGenomics our mission is save millions of lives by sharing knowledge on a global scale. We are passionate about high-quality and convenient healthcare. We are also passionate about privacy. We strive to comply with the General Data Protection Regulation (GDPR) and to be market leaders when it comes to privacy.

This policy explains how we use your personal data. We want to help you understand how we work with your data, so that you can make informed choices and be in control of your information. We invite you to spend a few moments understanding this policy. We may update this policy from time to time and, if we make any material changes, we will notify you when we do so. We will provide you with the opportunity to review such changes. By continuing to use our products and services after the changes have been made and we have notified you of them, the way we use your personal data will be subject to the terms of the updated policy.

This policy explains how we use your personal data for our services including, amongst others, our matchmaking services. It also governs the use of your data through our App, or any of our websites, including the Social Genomics website (and any reference to our App in this policy shall also include a reference to our websites).

This policy covers:

- Who we are;
- What personal data we hold and how we get it;
- What we use your personal data for;
- What lawful basis we have to use it;
- What lawful basis we have to use it;

- The type of parties we share it with;
- How we protect your personal data; and,
- What rights you have regarding your personal data.

This privacy statement applies to visitors of the Social Genomics website and patients that register themselves on the Social Genomics platform.

This statement was last updated on and will be reviewed and updated on a regular basis.

We have tried our best to make this statement as concrete and complete as possible. Please do not hesitate to contact us in case you have any questions or concerns regarding this statement:

If you have any further questions about how we process your information, please don't hesitate to get in touch by contacting us:

Email: contact@socialgenomics.co

About SocialGenomics

Our services are delivered by one company within our group which are both registered in the Netherlands: SocialGenomics B.V. (number70914524) provides the technology that supports our services.

SocialGenomics aspires to become the largest global community to connect patients, loved ones and passionate scientists to provide support, access to lifesaving information and accelerate medical breakthroughs. Through offering rare disease patients and people with cancer, relatives, friends, medical specialists, academics, hospitals, life science researchers access to a highly secure global community.

The protection of your personal data is important to us and we want to be transparent about the way we use your data. For this reason, we have drafted this statement to inform you about how we treat your personal data.

Our commitment to your privacy

We are committed to treating your personal data with care. We will use it according to the appropriate security standards and delete it once we do not need it anymore. We will only collect the personal data we need in order to fulfill the purposes we have communicated to you. Finally, we will keep your data as accurate and up to date as possible.

Who is responsible for your personal data?

Social Genomics is the controller for the processing of your personal data. Above you can find contact information if you want to use any of your rights regarding the personal data we have collected from you. “we”, “us” and “our” in this statement refers to SocialGenomics.

What we use your personal data for

The purposes for which we use your personal data and the legal grounds on which we do so are as follows:

- We obtain and use your personal details in order to establish and deliver our contract with you.
- We obtain and use your medical information because this is necessary for our matchmaking services.
- Where you have provided your explicit consent, we will use your medical information (always having removed personal identifiers, such as your name, address and contact details) to improve our healthcare products and services, and our artificial intelligence system, so that we can deliver better healthcare to you and other Social Genomics users. This medical information (de-identified in the way described above) may include information about your genetic disease condition. This does not involve making any decisions about you – it is only about improving our products, services and software so that we can deliver a better experience to you and other Social Genomics users, and help achieve our aim of creating a future with universal access to lifesaving information for all. Strict confidentiality and data security provisions apply at all times.
- We may use strictly anonymised information (including medical information) to improve our services.

Type of personal data	Purpose	Lawful basis
Browser history, such as pages accessed, date accessed and location from which website is accessed	To maintain and improve our website and monitor our website’s performance.	Our legitimate interests to maintain and improve our website according to visitor’s preferences, and monitor our website’s performance.
IP address	To be able to provide you access to our website	Our legitimate interests to make sure internet users can visit our website and access its contents
Contact information, such as your name and e-mail address	To contact you with the communication you requested, either a newsletter, or when you make a query on a contact page on our website	Your consent

<p>Contact information, such as your name and e-mail address Information about your medical condition/reason of registry</p> <p>Information about your status as a registrant (patient, loved one, supporter, doctor, scientist)</p>	<p>To register you on the Social Genomics platform</p>	<p>Your consent</p>
<p>Contact information, such as your name and e-mail address Information about your medical condition/reason of registry. Information about your status as a registrant (patient, loved one, supporter, doctor, scientist)</p> <p>Place of birth, data of birth Other medical information: Name medical condition e.g.: Usher syndrome, name mutation, found in gen research (PPN3) , name sort of mutation found in research (RS00015)</p> <p>Keywords or other additional information for better</p>	<p>To create a full profile of registrants to the Social Genomics platform</p>	<p>Your consent</p>

- We may obtain and use data about your precise location where you give your consent (through providing us access to your location), for example, to help direct you to other people like you in close proximity. We may also derive your approximate location from your IP address.
- We use your email address and/or phone number to contact you with occasional updates and marketing messages where you have not opted out, based on our legitimate interest in marketing our services to you and subject to your right to opt out at any time.
- Based on our legitimate interest in managing and planning our business, we may analyse data about your use of our products and services to, for example, troubleshoot bugs within the App, forecast demand of service and to understand other trends in use, including which features users use the most and find most helpful, and what features users require from us. This does not involve making any decisions about you - it is only about improving our App so that we can deliver better services to you. Strict confidentiality and data security provisions will apply at all times.
- Where necessary, we may need to share personal details for the purposes of fraud prevention and detection.

- We also store your medical information, such as notes from your connections with other users and shared content interactions with our digital services, for safety, regulatory, and compliance purposes.
- We may use non-personal data (data from which an individual cannot be identified) to improve our services.

Below follows an overview of the types of personal data we process from you.

We have also included the purpose we use this personal data for, and the lawful basis for the processing of your personal data. If we process your personal data in a substantially different way than mentioned below, we will inform you about this separately.

How long do we keep your personal data?

We keep your personal data for as long as this is necessary for the purposes we collected it for, within the legal limits and our own internal policies for retention.

Who do we share your personal data with?

We also share personal data with some third parties, summarized in the next section.

Sharing your personal data with others

- We may share your personal data with companies we have hired to provide services on our behalf, including those who act as data processors on our behalf, acting strictly under contract in accordance with Article 28 GDPR. Those data processors are bound by strict confidentiality and data security provisions, and they can only use your data in the ways specified by us.
- We may share with our commercial partners aggregated data that does not personally identify you, but which shows general trends, for example, the number of users of our service.
- We may preserve or disclose information about you to comply with a law, regulation, legal process, or governmental request; to assert legal rights or defend against legal claims; or to prevent, detect, or investigate illegal activity, fraud, abuse, violations of our terms, or threats to the security of our services or the physical safety of any person.

Except as described above, we will never share your personal information with any other party without your consent.

How we protect your personal data when we share it with parties that do not fall under European data protection rules

If we share personal data with an organization that does not fall under European data protection rules nor has an adequacy decision from the European Commission, we protect your personal data by using the Standard Contractual Clauses from the European Commission, which makes sure that the parties we share your personal data with uphold the same standards of data protection as we do.

How do we protect your personal data?

We care about protecting the availability, integrity and availability of your personal data. We have implemented a number of security measures to help protect your personal data. For example, we implement access controls, use the appropriate system and network security measures like firewalls, patching, and when used we protect portable devices with appropriate passwords.

Data storage, security and transfers

We do not store your personal health data on your mobile device. We store all your personal health data - including your personal information, medical condition, medication information and diagnostic information - on secure servers.

Where you have chosen a password that enables you to access certain parts of our App, you are responsible for keeping this password confidential. We ask you not to share the password with anyone.

We encrypt data transmitted to and from the platform. Once we have received your information, we will use strict procedures and security features to try to prevent unauthorised access. We will take all steps reasonably necessary to ensure that your data is treated securely and in accordance with this privacy policy.

Your data may be processed or stored via destinations outside of the Netherlands and the European Economic Area, but always in accordance with data protection law, including mechanisms to lawfully transfer data across borders, and subject to strict safeguards. For example, we work with third parties who help deliver our services to you, whose servers may be located outside the Netherlands or EEA.

Your rights

As indicated above, whenever we rely on your consent to process your personal data, you have the right to withdraw your consent at any time by accessing the privacy settings in the App.

You also have specific rights under the GDPR and DPA to:

- Wherever we process data based on your consent, withdraw that consent at any time. You can do this via the privacy section of our App;

- Understand and request a copy of information we hold about you. For other information, you can make a request by email;
- Ask us to rectify or erase information we hold about you;
- Ask us to restrict our processing of your personal data or object to our processing; and
- Ask for your data to be provided on a portable basis.

The right to access correct and receive a copy of your personal data

It is important to us that the personal data we hold about you is accurate, up to date, complete, relevant and not misleading. In order to ensure we uphold this commitment, you have the right to access, correct or update your personal data at any time. Upon request, we will also provide you with a copy of the personal data we hold from you.

The right to data portability

You are entitled to receive your personal data in a structured, commonly used and machine-readable format if we have processed your personal data for the following legal grounds:

1. a) You have given consent to us to process your personal data for a purpose that we have communicated to you beforehand; or
2. b) We have processed your personal data in order to facilitate a contract with you; or
3. c) We have processed your personal data using automated means (such as profiling).

The right to deletion of your personal data

You have right to request that we delete your data if:

- a) Your personal data is no longer necessary in relation to the purposes for which we collected it; or

- b) You withdraw the consent that you had previously given us to process your personal data,

and there is no other legal ground to process that personal data; or

- c) You object to us processing your personal data for our legitimate interests;
 d) The personal data is not being processed lawfully; or
 e) Your personal data needs to be deleted to comply with relevant legal requirements.

If you wish to delete the personal data we hold about you, please let us know and we will take reasonable steps to respond to your request in accordance with legal requirements.

If the personal data we collect is no longer needed for any purposes and we are not required by law to retain it, we will do what we can to delete, destroy or permanently anonymize it.

The right to restriction of processing

You have the right to request the restriction of processing your personal data if:

- a) You do not believe the personal data we have about you is accurate; or
 b) The personal data is not being processed lawfully, but instead of deleting the personal data,

you would prefer us to restrict processing instead; or

c) We no longer need your personal data for the purposes we collected it, but you require the

data in order to establish, exercise or defend legal claims; or

d) You have objected to the processing of your personal data and are awaiting verification on

whether your interests related to that objection outweigh the legitimate grounds for processing your data.

If you wish to restrict our processing of your personal data, please let us know and we will take reasonable steps to respond to your request in accordance with legal requirements.

The right to object or withdraw consent

You have the right to object to the processing of your personal data at any time, if the processing is based on our legitimate interests (see section 4 for an overview). You have the right to withdraw

consent for the processing of your personal data at any time, if the processing is based on your consent (see section 4 for an overview).

The right to lodge a complaint with a supervisory authority

You have the right to lodge a complaint directly with the data protection authority about how we process your personal data. Please find a link here with an overview of the relevant authorities.

Cookies

A cookie is a small piece of data that a website asks your browser to store on your computer or mobile device. The cookie allows the website to "remember" your actions or preferences over time.

Most browsers support cookies, but users can set their browsers to decline them and can delete them whenever they like.

We also use cookies on our website. We use Google analytics, a service that provides us insight into the way in which our website is used such as usage statistics about the number of different visitors, the pages that are visited and the average duration of a visit. We have a processor agreement with Google to ensure that personal data collected in the context of Google Analytics will only be used to provide us insight into the way in which our website is used. We have also adjusted the settings of the service in such a way that the personal data may not be used by other Google services, and the last digits all IP addresses collected in this context are immediately deleted to make it more difficult to identify a specific visitor.

Date: 22 May 2019

