

Genetic Health Map Privacy Notice

At Kyowa Kirin International plc, we are committed to protecting and respecting your privacy.

Please read this Privacy Notice, together with any other privacy notice that we may provide to you, as it contains important information about how we collect, manage, use and protect your personal data. This Privacy Notice may also be used in conjunction with other privacy notices that we may provide you with in certain situations.

We may change this Privacy Notice from time to time. Please check this notice frequently to ensure you are aware of the most recent version and the date that it was last updated.

This policy was last updated in July 2019.

If you have any questions regarding this notice or about our privacy practices, please contact us on the below details:

- E-mail: KKIDPOoffice@kyowakirin.com
- Post: Kyowa Kirin International Ltd, Head Office, Galabank Business Park, Galashiels, TD1 1QH, United Kingdom and marking your query for the attention of The Data Protection Officer
- Telephone: +44 1896 664 0000

Who are we?

Kyowa Kirin International plc is part of the Kyowa Hakko Kirin Group. The Group is made up of different legal entities, details of which can be found [here](#) and which may be updated from time to time. When we say 'KKI', 'we' or 'us' in this policy, we are referring to the relevant company in the Kyowa Hakko Kirin Group responsible for processing your personal data.

KKI is a "data controller" of the personal data that we hold about you. This means that we are responsible for deciding how we hold and use personal information about you. We are required under data protection legislation to notify you of the information contained in this privacy notice.

What information do we collect?

Personal data, or personal information, means any information about an individual from which that person can be identified. It does not include data where the identity has been removed (anonymous data).

In your use of the Pedigree tool, we will collect the following information about you:

- **Identity Data** including your name and employer;
- **Contact Data** including your email address;

- **Technical Data** including the Internet protocol (IP) address used to connect your computer to the Pedigree tool, your login information, browser type and version, time zone setting, browser plug-in types and versions, operating system and platform;
- **Usage Data** including your usage of the Pedigree tools.

How do we collect your information?

- **Information you give us.** You may give us such information directly by registering with us or by corresponding or speaking with us or our processor by phone, email, letter or otherwise.
- **Information we collect about you.** When you use our tool and receive e-mails from us we may collect technical information about your use of the tool, frequency of use and patterns of use.

How we might use your information?

We use information held about you in the following ways:

- To provide the Pedigree tool;
- To manage and administer our relationship with you;
- To carry out our obligations arising from any contracts entered into between you and us or us and your employing institution;
- To respond to your requests;
- To notify you about changes to our service; and
- To assess and analyse the use of the Pedigree tool.

What is our legal basis for using your information?

There are a number of lawful reasons for us to process your personal data.

One of these is called 'legitimate interest' and means that we can process your personal data if (i) we have a genuine and legitimate reason; and (ii) are not harming any of your rights and interests in an unwarranted manner. All of the purposes identified above, unless you have directly entered into a contractual arrangement with KKI for the Pedigree tool, are based on our legitimate interest. If you have a contractual arrangement with KKI yourself to access the tool, we will process your data for the purposes of fulfilling the contract between us.

Whenever we process your personal data for our legitimate interests, we will consider and balance any potential impact on you and your rights under data protection law.

Where we are required to comply with our legal obligations, or to establish and defend our legal rights, or to prevent and detect crimes such as fraud, we will also process data for this reason.

How long will we hold your information for?

We will hold your personal data on our systems for as long as is necessary to fulfil the purposes that we collected it for, including for the purposes of satisfying any legal, accounting or other reporting requirements.

By law, we are required to retain certain information for a prescribed period of time. In circumstances where there are no such legal requirements, to determine the appropriate retention period, we will consider the amount, nature and sensitivity of the personal data, the potential risk of harm from unauthorised use or disclosure of your personal data, the purposes for which we are processing your personal data and whether we can achieve those purposes through other means.

Therefore, some information may be kept for a longer or shorter period depending on the purpose for which the data is processed

We review our retention periods for personal data on a regular basis.

In some circumstances we may anonymise your personal data (so that it can no longer be associated with you) for research or statistical purposes in which case we may use this information indefinitely without further notice to you.

If you ask us to delete your information in accordance with your rights set out below, we will retain basic information on a suppression list to record your request and to avoid sending you unwanted materials in the future.

Who we might share your information with

We may share your information with selected third parties when we use other companies to provide services on our behalf, e.g. providing the Pedigree tool platform, providing support and anonymising and aggregating your data.

We may disclose your personal information to third parties to:

- Comply with any court order or other legal obligation or when data is requested by our regulators or by government agencies or law enforcement;
- Enforce or apply our terms of use and any other agreements;
- Protect the rights, property, or safety of us, our employees or others. This may include exchanging information with other companies and organisations for the purposes of fraud protection and credit risk reduction.

If you fail to provide personal data

Where we need to collect in order to provide the Pedigree tool, you will not be able to gain access to the tool. These fields are marked as mandatory on registration. All other provision of data is voluntary.

Your rights

You have a number of rights. If you would like to exercise any of these rights, please contact us using the details set out below in the 'Contact Us' section. If you exercise any of these rights we may ask for proof of identity and sufficient information about your interactions

with us so that we can locate your personal information. If we agree that we are obliged to provide personal information to you (or someone else on your behalf), we will provide it to you or them free of charge except in exceptional circumstances.

You also have the right to lodge a complaint with the data protection regulator, the Information Commissioner's Office, if you have concerns about how we use your personal information. You can contact the Information Commissioner's Office at: <https://ico.org.uk/global/contact-us/>.

Your rights include:

- transparency over how we use your data and to make a subject access request (right of access);
- a right to have your personal data updated and corrected (right of correction/rectification)
- a right to ask us to delete your information (right to be forgotten);
- a right to ask us to stop processing your information (right to restriction);
- a right to object to (i) processing based on our legitimate interests; (ii) processing of your information for direct marketing purposes; and (iii) automated decision making and profiling (right to object);
- a right to receive a copy of your information, or have this sent to a third party (right to data portability); and
- a right to claim compensation for material or non-material damage caused if we breach the data protection rules (right to compensation).

If you would like to find out more about your rights, you can visit the Information Commissioner's Office website (<https://ico.org.uk/for-organisations/guide-to-the-general-data-protection-regulation-gdpr>).

How you can access and update your information

We strive to maintain accurate, complete, and relevant personal information for the purposes identified in this privacy statement. If any of the personal information we hold about you is inaccurate or out of date, you may ask us to correct it. It is important that the personal information we hold about you is accurate and current.

Security precautions in place to protect against the loss, misuse or alteration of your information

We have implemented reasonable measures designed to secure your personal information from accidental loss and from unauthorized access, use, alteration and disclosure. Details of these measures can be obtained on request.

Third parties will only process your personal information on our instructions and where they have agreed to treat the information confidentially and to keep it secure.

We also have procedures in place to deal with any suspected data security breach. We will notify you and any applicable regulator of a suspected data security breach where we are legally required to do so.

Our security measures are regularly reviewed.

Contact Us

If you have any questions regarding this policy or about our privacy practices, wish to exercise any of your rights or wish to make a complaint, please contact our Data Protection Officer at:

- E-mail: KKIDPOoffice@kyowakirin.com
- Post: Kyowa Kirin International Ltd, Head Office, Galabank Business Park, Galashiels, TD1 1QH, United Kingdom and marking your query for the attention of The Data Protection Officer
- Telephone: +44 1896 664 0000