

International Genetic Epidemiology Society (IGES)

GDPR Compliance Statement

Introduction

The **EU General Data Protection Regulation (“GDPR”)** came into force across the European Union on 25th May 2018 and brings with it the most significant changes to data protection law in two decades. Based on privacy by design and taking a risk-based approach, the GDPR has been designed to meet the requirements of the digital age.

The 21st Century brings with it broader use of technology, new definitions of what constitutes personal data, and a vast increase in cross-border processing. The new Regulation aims to standardise data protection laws and processing across the EU; affording individuals stronger, more consistent rights to access and control their personal information.

Our Commitment

The International Genetic Epidemiology Society (IGES) is committed to ensuring the security and protection of the personal information that we process, and to provide a compliant and consistent approach to data protection. We have always had a robust and effective data protection program in place which complies with existing law and abides by the data protection principles. However, we recognise our obligations in updating and expanding this program to meet the demands of the GDPR.

IGES is dedicated to safeguarding the personal information under our remit and in developing a data protection regime that is effective, fit for purpose and demonstrates an understanding of, and appreciation for the new Regulation. Our preparation and objectives for GDPR compliance have been summarised in this statement and include the development and implementation of new data protection roles, policies, procedures, controls and measures to ensure maximum and ongoing compliance.

Our preparations for the GDPR

IGES has always had a consistent level of data protection and security across our organisation, however it is our aim to be fully compliant with the GDPR now it has come into force on 25th May 2018. ***Our preparations have included:*** -

- ***Information Audit*** - carrying out an audit to identify and assess what personal information we hold, where it comes from, how and why it is processed and if and to whom it is disclosed.
- ***Policies & Procedures*** - revising our data protection policies and procedures to ensure we meet the requirements and standards of the GDPR and any relevant data protection laws.
- ***Legal Basis for Processing*** - we are reviewing all processing activities to identify the legal basis for processing and ensuring that each basis is appropriate for the activity it relates to. Where applicable, we also maintain records of our processing activities,

ensuring that our obligations under Article 30 of the GDPR and Schedule 1 of the Data Protection Bill are met.

- **Privacy Notice/Policy** – we are revising our Privacy Notice(s) to comply with the GDPR, ensuring that all individuals whose personal information we process have been informed of why we need it, how it is used, what their rights are, who the information is disclosed to and what safeguarding measures are in place to protect their information.
- **Obtaining Consent** - we are revising our consent mechanisms for obtaining personal data, ensuring that individuals understand what they are providing, why and how we use it and giving clear, defined ways to consent to us processing their information. We have developed stringent processes for recording consent, making sure that we can evidence an affirmative opt-in, along with time and date records; and an easy to see and access way to withdraw consent at any time.
- **Direct Marketing** - we are revising the wording and processes for direct marketing, including clear opt-in mechanisms for marketing subscriptions; a clear notice and method for opting out and providing unsubscribe features on all subsequent marketing materials.

Data Subject Rights

In addition to the policies and procedures mentioned above that ensure individuals can enforce their data protection rights, we respect an individual's right to access any personal information that **IGES** processes about them and to request information about: -

- What personal data we hold about them
- The purposes of the processing
- The categories of personal data concerned
- The recipients to whom the personal data has/will be disclosed
- How long we intend to store your personal data for
- If we did not collect the data directly from them, information about the source
- The right to have incomplete or inaccurate data about them corrected or completed and the process for requesting this
- The right to request erasure of personal data (*where applicable*) or to restrict processing in accordance with data protection laws, as well as to object to any direct marketing from us and to be informed about any automated decision-making that we use
- The right to lodge a complaint or seek judicial remedy and who to contact in such instances

Information Security & Technical and Organisational Measures

IGES takes the privacy and security of individuals and their personal information very seriously and take every reasonable measure and precaution to protect and secure the personal data that we process. We have robust information security policies and procedures in place to protect personal information from unauthorised access, alteration, disclosure or destruction.

GDPR Roles and Employees

IGES has designated the IGES **Secretary** and **Treasurer** as our joint **Data Protection Officers** with the responsibility to develop and implement our roadmap for complying with the new data protection Regulation.

If you have any questions about our preparation for the GDPR, please contact us by email at **iges@geneticepi.org**