

Personal data security in TruSight™ Software Suite

TruSight Software Suite is designed to comply with the seven principles of data processing specified by the GDPR.

Introduction

Whole-genome sequencing (WGS) using next-generation sequencing (NGS) technology provides a high-resolution, unbiased view across the entire genome to discover causative variants associated with rare diseases. Illumina offers TruSight Software Suite, a software as a service (SaaS) analytics solution that helps translate raw sequencing data into meaningful results. TruSight Software Suite delivers efficiency and high confidence to customers using the software for case management, variant analysis, and interpretation in rare disease.

General Data Protection Regulation

The General Data Protection Regulation (GDPR) is a European Union (EU) regulation that addresses data protection and privacy in the EU and European Economic Area (EEA) as well as transfer of personal data outside the EU and EEA. The GDPR specifies personal data as “any information that relates to an individual who can be directly or indirectly identified.”¹ Organizations that process data of individuals living in the EU must do so according to seven principles (Figure 1):

- Lawfulness, fairness, and transparency
- Purpose limitation
- Data minimization
- Accuracy
- Storage limitation
- Integrity and confidentiality (security)
- Accountability



Figure 1: GDPR specifies seven principles for personal data processing

TruSight Software Suite compliance with GDPR

Illumina has designed TruSight Software Suite to help customers adhere to data protection and privacy standards forth by the GDPR. This technical note describes how TruSight Software Suite complies with the seven principles for personal data processing (Table 1).

Table 1: Adherence and compliance to the seven principles of GDPR

Principle	Description	How TruSight Software Suite helps customers comply
Lawfulness, fairness, and transparency	Customers must identify lawful basis for processing personal data in a fair and transparent manner.	Illumina will not use personal data processed through TruSight Software Suite for other purposes.
Purpose limitation	Customers must disclose legitimate purposes for collecting personal data.	Illumina will only use personal data for providing TruSight Software Suite service.
Data minimization	Customers must collect only as much personal data as is necessary for the purpose specified.	Illumina does not have access to personal data stored in an instance of TruSight Software Suite.
Accuracy	Customers must ensure that personal data that is collected is accurate and up to date.	Illumina has designed and verified TruSight Software Suite to maintain data accuracy and integrity.
Storage limitation	Customers must retain personal data only for as long as is necessary for the specified purpose.	Illumina has designed TruSight Software Suite to include personal data purges 30 days after account expiry.
Integrity and confidentiality (security)	Customers must maintain personal data confidentiality and security.	TruSight Software Suite has been certified according to the ISO-27001:2013 security standard.
Accountability	Customers must demonstrate compliance with all GDPR principles.	TruSight Software Suite includes measures for handling and securing personal data to adhere to GDPR standards.

Lawfulness, fairness, and transparency

Our customers are responsible for identifying an appropriate lawful basis (there are six available bases pursuant to the GDPR) for processing personal and sensitive personal data through TruSight Software Suite.

Illumina will not, without express consent, use any personal or sensitive personal data processed through TruSight Software Suite by the customer for any purposes other than delivering the service to the customer and related technical support. Additional details about how Illumina uses customer information/data can be found in the Illumina Corporate Privacy Policy. Where applicable, Illumina keeps a record of its processing activity, eg, log files automatically generated by TruSight Software Suite, to ensure proper functionality.

Purpose limitation

Customers are responsible for disclosing to individuals (data subjects) their purposes for processing and aggregating personal data and sensitive personal data.

Illumina will only use personal data and sensitive personal data as directed by the customer and in the performance of providing the TruSight Software Suite service and related technical support.

Data minimization

TruSight Software Suite is designed for analyzing and interpreting genetic information. The software enables users to collect and track a wide range of personal and sensitive personal data; however, it only requires the sex of the sample and relationship to other samples in a particular case for proper quality control and data processing. All other information is optional. TruSight Software Suite customers are responsible for periodic review of their own data minimization practices in their use of the software.

Illumina does not have access to personal data or sensitive personal data stored within the customer's instance of TruSight Software Suite. In order to provide some types of technical support, the customer will need to share, through secure channels, data, screenshots, or other medium outside of their instance of TruSight Software Suite. Any technical support will be handled by Illumina staff that are trained in data protection and data handling practices.

Accuracy

Customers are responsible for ensuring that the personal data and sensitive personal data they upload into TruSight Software Suite are accurate. Illumina provides the functionality within TruSight Software Suite for customers to store and edit this information to maintain accuracy.

Illumina has designed and verified the TruSight Software Suite service to ensure that the accuracy and integrity of genetic data are maintained. Should customers find an inaccurate representation of genetic information, we ask them to notify Illumina, where we have processes in place to respond to such feedback and continuously improve TruSight Software Suite.

Storage limitation

TruSight Software Suite provides customers with the ability to delete personal and sensitive personal data according to their own data retention schedules. Expired accounts will have their data purged after a 30-day grace period, during which time we will make our best efforts to contact the customer. Backups of personal data and sensitive personal data are maintained for up to 14 days within the same global region of the deployed instance of TruSight Software Suite.

Integrity and confidentiality (security)

TruSight Software Suite has been developed under the strict design and operational controls required by Illumina management systems. The Illumina Information Security Management System is certified according to ISO-27001:2013, with information services suppliers that implement a collection of physical, administrative, and technical controls to protect customer data. The Illumina Quality Management System is certified according to ISO-13485, to provide risk management, product design control, and product support that ensure the integrity of the data and services that are provided to Illumina customers.

Accountability

As described in the Illumina Corporate Privacy Policy, Illumina takes steps and implements measures for handling and securing personal data and sensitive personal data to which it has access. Illumina has appropriate measures and records in place to demonstrate that TruSight Software Suite adheres to the principles of GDPR and has, accordingly, completed a data privacy impact assessment for TruSight Software Suite.

Summary

TruSight Software Suite offers an intuitive and comprehensive rare disease analysis and interpretation solution. Illumina has designed TruSight Software Suite to meet data protection and privacy standards forth by the GDPR and comply with the seven principles for personal data processing.

Learn more

Learn more about TruSight Software Suite at www.illumina.com/trusight-software-suite

References

1. General Data Protection Regulation (GDPR) - Official Legal Text. gdpr-info.eu/. Accessed June 22, 2020.