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Preceptor Senior Inspector of the Data Protection Inspectorate Helina-Aleksandra Lettens Date and place of issue of the precept 19.11.2018 Tallinn Addressee of the precept - processor of personal data University of Tartu Institute of Genomics address: Riga 23b, 51010 Tartu e-mail address: genoomika@ut.ee Chief official of the personal data processor director

RESOLUTION: 751 (4); Pursuant to § 32 (1) and § 40 (1) of the Personal Data Protection Act (IKS), I issue a mandatory precept to comply with: wishes and issue the relevant information. The release of data can only be refused if there is a legal basis and the refusal must be duly substantiated. I set 19.12.2018 as the deadline for compliance with the precept. Notify the Data Protection Inspectorate of the fulfillment of the precept by that deadline at the latest. CONTEST REFERENCE: This precept can be challenged within 30 days by submitting either: - a challenge under the Administrative Procedure Act to the Data Protection Inspectorate, or - an appeal under the Code of Administrative Court Procedure to the Tallinn Administrative Court (in which case the challenge can no longer be heard). Contestation of a precept does not suspend the obligation to comply with the precept or the application of the measures necessary for compliance. WARNING If a processor of personal data fails to comply with a precept of the Data Protection Inspectorate, the Data Protection Inspectorate may apply to a higher authority, person or the whole of the personal data processor for official supervision or disciplinary proceedings against an official pursuant to subsection 40¹ (1) of the Personal Data Protection Act. PENALTY OF WARRANTY: If the precept is not complied with by the specified term, the Data Protection Inspectorate shall impose a penalty payment of 1,500 (one thousand five hundred) euros on the addressee of the precept on the basis of subsection 40 (2) of the Personal Data Protection Act. The penalty payment may be imposed repeatedly - until the precept is complied with. If the addressee does not pay the penalty payment, it is forwarded to the bailiff to start enforcement proceedings. In this case, the bailiff's fee and other enforcement costs are added to the penalty payment. FACTUAL CIRCUMSTANCES: xxxxxxxxxx complaint concerning the release of personal data was registered with the Data Protection Inspectorate. According to the complaint, xxxxxxxxxx submitted an application to the Institute of Genomics of the University of Tartu for data about himself. In that application, he asked for a description of his DNA. The complaint shows that the Institute of Genomics does not have the relevant rules of procedure and technical solution, which means that the data cannot be released. EXPRESSION OF THE PERSONAL DATA PROCESSOR:

The following are our answers to your questions. 1. For what reasons has the Gene Bank not complied with the application

submitted by xxxxxxxxxxxx? Xxxxxxxxxxxxxx is the first gene donor to apply to the Gene Bank for a DNA profile. Therefore, the Gene Bank did not previously have a precise idea of the scope of the procedure and the details and obstacles involved. 2. Is the release of genetic data regulated by a special law? If so, please indicate the law and the corresponding provision. The release of gene donor data is regulated by the following provisions of the Human Gene Research Act: § 11. Other rights of gene donors (1) A gene donor has the right not to know his or her own genetic data. (2) A gene donor has the right to personally examine the information stored in the gene bank concerning him or her. A gene donor does not have the right to inspect his or her family tree. (3) A gene donor shall not be charged a fee for access to information stored in the gene bank concerning him or her. (4) A gene donor has the right to genetic counseling upon examination of information concerning him or her stored in the gene bank. § 16. Permissibility of use of gene bank (2) In order to treat a gene donor, a doctor of a gene donor has the right to receive a coded description of the health status of the gene donor in accordance with clause 24 (2) 7) of this Act. As the Gene Bank has not yet released data on the description of their DNA to gene donors in a form that cannot be read / interpreted, so to speak, without expert knowledge, the Gene Bank did not have a definitively agreed procedure for issuing such data to gene donors. As a DNA description, today we can interpret the data in the Gene Bank at three different levels: a) Raw data from the DNA description - preliminary data from the results of the gene chip test; (b) DNA profile data (quality controlled); (c) Genetic risk reports based on DNA characterization, currently available through an advisor. To date, a precise procedure and technical solution for the release of the last two items of the list have been developed. The Gene Bank does not consider it appropriate to release raw DNA description data to a gene donor, as this may be misleading. 4. Please provide any views, explanations and justifications you consider necessary in this 3 (3) case. We consider it important to add that despite the fact that the law prescribes the right of a gene donor to know and examine the (gene) data stored in the Gene Bank, the Republic of Estonia has not financed the Gene Bank to create the technical solutions necessary for these activities. Until now, the Republic of Estonia has funded the Gene Bank for the collection of gene samples and data, DNA isolation, DNA genotyping and the creation of DNA profiles, but not for the issuance of DNA profiles to gene donors. The gene bank is ready to release the requested data to the gene donor according to the developed procedure as soon as its data has been checked and the data file has been compiled, but not later than within two months.

FOUNDATIONS FOR THE DATA PROTECTION

INSPECTORATE: The Gene Bank has been collecting personal data for almost 20 years and the Personal Data Protection Act, together with the right to receive information about oneself and personal data, entered into force in Estonia 22 years ago.

Therefore, there can be no acceptable justification for the lack of procedural rules and technical means to release the data.

Both the Personal Data Protection Act and the General Data Protection Regulation stipulate that the data subject must be able to exercise the right of access to all data concerning him or her. This legislation does not allow the data to be refused on the grounds that the data may be misleading and that the controller does not have the rules or technical capacity to release the data. A person's right to information and personal data concerning him or her shall be restricted only if this may prejudice the rights and freedoms of another person, jeopardize the protection of the secrecy of the child's origin, prevent the crime or apprehend the offender or make it more difficult to establish the truth in criminal proceedings. It can be understood from the explanations of the gene bank that DNA profile data in a form that cannot be read and interpreted without professional knowledge can be consulted together with an on-site consultation pursuant to § 11 (2) and (4) of the Human Gene Research Act. he will still have the right to request this data under the Personal Data Protection Act or the General Regulation, whether or not he or she can read and interpret this data. In principle, a person has the right to request interpretations at all three levels (raw DNA profile data, DNA profile data that has passed quality control, and genetic risk reports based on DNA profile). In the interests of clarity, the Institute of Genomics of the University of Tartu must find out exactly which applicant the applicant wishes to be issued. It is possible that a person does not want to issue interpretations at all three levels. As this is currently the only such application and the application has already been submitted in the beginning of September, the data must be released by 19 December 2018 at the latest. / digitally signed / Helina-Aleksandra Lettens Senior Inspector Authorized by the Director General