**Appendix to Informed Consent Form: Information to be provided in relation to the EU’s General Data Protection Regulation, GDPR, Article 13**

As a participant in the EuroSIDA study and the RESPOND data repository, below please find the description of the procedures in connection with collection and protection of your data, as well as your rights regarding the data collection, in case this is not described in the Patient Information.

**Purpose and legal basis for the prossesing of your personal data**

We will use your personal data including blood samples for the purpose described in the **Patient Information and Informed Consent for EuroSIDA.**

The legal basis for our processing of your personal information follows from:

* + - * Permission from the Danish Scientific Ethics Committee, cf. the Danish Act on the Scientific Ethical Treatment of Health Science Research Projects with the consent of the data subject.
      * Consent from you to obtain information from your journal as an authorized healthcare professional for use in the specific project, cf. Section 42d (1) of the Danish Health Act. The subsequent processing and storage follow from the consent requirements of Articles 6 and 9 of the General Data Protection Regulation and preamble 32-33.

**Categories of personal data**

We only process the personal data related to you that are described in the Patient Information.

**Data processors**

We process your data for the described purpose of the study. We may securely share your data with other investigators for processing related to the study. The data shared are pseudonymised. Investigators comply with the same laws and policies to protect your data as we do.

The following are external data processors who, on our behalf, process your data for the purpose of the study:

• Computerome: Server/it-system

• IrsiCaixa: Bioinformatics analyses

• Swiss HIV Cohort Study: Biostatistical analyses

• University College London: Biostatistical analyses

• Kirby Institute: Statistical analyses

For further information regarding the data processors, please contact the primary project responsible.

**Transfer to new data controller**

If we are contacted by another data controller for the purpose of disclosing project data about you, we will, prior to the disclosure of your data, contact you for consent to transferring your information to a new data controller for their individual use.

**From where do we collect your personal data?**

It is described in the Participant Information from where we have collected your personal data.

**Storage of your personal data**  
At the present moment we cannot confirm for how long your personal data will be kept on file. However, when it is decided for how long your data will be kept on file, importance will be attached to: the study period; the time needed for data analyses to be able to answer the purpose described in the participant information; and the period of time the authorities in the participating countries require that the information is kept on file after the study is completed.

**The right to withdraw consent**

You have the right to withdraw your consent from the study at any time. To do that contact the study team at your site.

If you chose to withdraw your consent, we will still be able to use your personal data already collected on basis of your previous consent up until the time of withdrawal. If you withdraw your consent, it will have effect from the time of withdrawal and onwards.

**Your rights**

According to General Data Protection Regulation you have a number of rights in relation to our processing of your personal data.

If you want to use your rights, please contact the person responsible for the study.

**Right to deletion of data**

Special regulations apply in relation to statistical and scientific investigations, including research cf. General Data Protection Regulation article 17, paragraph 3, litra d. This means that we are allowed to keep on file and use the data we have already collected in order to assure that study results are accurate.

**Right to transfer data (data portability)**

In some cases, you have the right to receive your personal data in an organised, regularly used and machine-readable format and to have these personal data transferred from one controller to another without hindrance.

**Some rights are exempt in statistical and scientific investigations, including research**

This is to assure that the study results are accurate and not biased.

**Complaints to the Data Protection Agency**

You are entitled to file a complaint to the Data Protection Agency in case you are unsatisfied with the way we process your personal data. You can find contact information to the Data Protection Agency here: www.datatilsynet.dk/english/

**Contact information**

**Primary project responsible**

The primary project responsible is the person responsible for the execution of the study:

Primary project responsible Prof. Jens Lundgren.

Contact person Jakob Friis Larsen

Rigshospitalet, University of Copenhagen

CHIP, Department of Infectious Diseases, Section 2100

Finsencentret

Blegdamsvej 9

DK-2100 Copenhagen Ø, Denmark

Telephone number: +45 35455793

E-mail: [respond.rigshospitalet@regionh.dk](mailto:respond.rigshospitalet@regionh.dk)

**Data controller**

Region Hovedstaden is data controller of the processing of your study data:

Region Hovedstaden/ v. Videnscenteret for Dataanmeldelser

Blegdamsvej 9, 2100 Copenhagen Ø, Denmark

Mail: [videnscenteretfordataanmeldelser.rigshospitalet@regionh.dk](mailto:videnscenteretfordataanmeldelser.rigshospitalet@regionh.dk)

**Contact information for the Data Protection Officer (DPO) for the data controller**

If you have questions to the processing of you study data, you are always welcome to contact the DPO: Birgitte Hagelskjær Nielsen, Region Hovedstaden

Phone: +45 5116 2935

E-mail: [birgitte.hagelskjaer.nielsen@regionh.dk](mailto:birgitte.hagelskjaer.nielsen@regionh.dk)