# Information about storage of samples at Statens Serum Institut

Statens Serum Institut (SSI) handles a variety of tasks for the benefit of public health, such as analysing certain samples (e.g. blood samples and saliva samples) for the Danish healthcare system. If surplus sample material remains after analysis, it may be stored in the Danish National Biobank at SSI. You and everyone else from whom SSI stores samples receive this information as we are obligated to do so according to the rules regarding processing of personal data (GDPR).

At SSI, we work with the diagnostics of special infections, prevention and control of diseases, and other tasks for the benefit of public health. In this context, we need to process personal data (both samples and data about samples). Sometimes SSI also receives samples only for scientific research purposes, which are stored in the Danish National Biobank. SSI's tasks are described in § 222 of The Danish Health Care Act.



We store samples for re-analysis and method development The reason we store samples after analysis is that, in consultation with your doctor, we can use them for new analyses if necessary. Additionally, the samples can be used to optimize and develop the analyses we conduct, so that doctors can continue to make the correct diagnosis and find the appropriate treatment in the future.



## We store samples for research

The samples may be used for specific research projects. Permission from a public ethics committee is required before the samples are released for research. If you are registered in The National Database of Non-Consent to the Use of Tissue Samples for Scientific Purposes, samples from you will not be used for research.

## No action is required

If you have no objections to SSI's continued storage of samples from you, you don't need to take any action.

## Your rights

The General Data Protection Regulation (GDPR) is a set of rules that grants you some rights. Among other things, you can be informed about which samples we store. You can find detailed information on how we process personal data and your rights when we store samples in the Danish National Biobank here: <u>www.ssi.dk/opbevaring</u>





## You can register with The National Database of Non-Consent to the Use of Tissue Samples for Scientific Purposes

If you do not want samples collected from you to be used for research, you can register with The National Database of Non-Consent to the Use of Tissue Samples for Scientific Purposes at the Danish Health Data Authority. Read more on the Danish Health Data Authority's website: www.sundhedsdata.dk/var

#### **Possibility of destruction**

If you wish to have samples, we have from you, destroyed, you can contact SSI via Digital Post. See how to do so here: <u>www.ssi.dk/sikkerkommunikation</u>. Be aware that samples cannot be recreated once destroyed.

#### Information about new samples

If we do not hear from you, we will continue to store the samples. If we, in the future, receive a new sample from you for analysis, you will be notified.

#### Heel prick test from newborns

If you were born in Denmark after 1975 and had a heel blood sample (PKU test) taken at birth, the analysis of the sample was performed by SSI. On our website <u>https://en.ssi.dk/personaldata</u> under the section: "Are you born after the year 1975?", you can read more about how we process personal data in connection with newborn screening.



#### Do you have any questions?

You're welcome to contact our call centre by phone by dialing 3232 1060. You can find the phone hours here: <u>www.ssi.dk/samples</u>

You can also contact SSI via Digital Post. See how to do so here: <u>www.ssi.dk/sikkerkommunikation.dk</u>, or send an email to the Department for Data Protection and Information Security at <u>SSIpersonoplysninger@ssi.dk</u>



#### **Right to complain**

You have the right to complain to the Danish Data Protection Agency (Datatilsynet) about SSI's processing of personal data about you. Here you can find the contact information for the Danish Data Protection Agency <u>www.datatilsynet.dk/english</u>

Statens Serum Institut Artillerivej 5 DK-2300 Copenhagen S



Version 6. • September 2024