

# Your genetic data, your choice

## Guidance for you if you have had a comprehensive genetic analysis



DANISH NATIONAL  
GENOME CENTER

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### What happens to your genetic data?

If you have had a comprehensive genetic analysis in connection with your treatment, your genetic data will be stored in the Danish National Genome Center. Your genetic data are stored in the Danish National Genome Center for the sake of your specific treatment. The data can also be used in connection with supervisory, complaint and compensation cases etc. within the health service.

In Patient information on comprehensive genetic analysis ("Patientinformation om omfattende genetisk analyse"), you can read more about the purposes for which your genetic data can be used. You can also read more about the Danish National Genome Center at [www.ngc.dk](http://www.ngc.dk).

### Your genetic data - you decide

Your genetic data may be used for research *unless* you decide that it may only be used for your own treatment and for purposes directly related to your treatment.

You can do this by registering with the National Database of Non-Consent to the Use of Tissue Samples for Scientific Purposes (Vævsanvendelsesregister). You can register electronically with your NemID at [www.borger.dk](http://www.borger.dk). You can also fill in and submit the form, which can be found at the bottom of the page. You can also deregister from the register if you change your mind.

It will not be possible to use your genetic data in research projects if you are registered in the National Database of Non-Consent to the Use of Tissue Samples for Scientific Purposes.

### Special genetic information from prenatal testing

If the comprehensive genetic analysis has been performed in connection to prenatal testing, the phrase "your genetic information" on the form refers to both the genetic information of you and the fetus. This means that you have to register yourself in the National Database of Non-Consent to the Use of Tissue Samples for Scientific Purposes (Vævsanvendelsesregister) if you do not wish for your information for your fetus/and or yourself to be included in health research.

### Registration via digital mail at [www.borger.dk](http://www.borger.dk)

1. Log in with NemID
2. 'Skriv ny post' (write new mail)
3. 'Vælg modtager' (Choose recipient)
4. Search: "Sundhedsdatastyrelsen" (Danish Health Data Authority)
5. Select: 'Til- og framelding til Vævsanvendelsesregisteret' (Registration with and deregistration from the National Database of Non-Consent to the Use of Tissue Samples for Scientific Purposes)

A more detailed guide can be found on the website (in Danish): [www.sundhedsdatastyrelsen.dk/da/borger/selvbetjening\\_og\\_services/brug\\_af\\_vaevsproever](http://www.sundhedsdatastyrelsen.dk/da/borger/selvbetjening_og_services/brug_af_vaevsproever)



## Registration with and deregistration from the National Database of Non-Consent to the Use of Tissue Samples for Scientific Purposes regarding genetic data in the Danish National Genome Center

Civil reg. no.: 

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Name: \_\_\_\_\_

Date: \_\_\_\_\_

Street: \_\_\_\_\_

Postal code./city: \_\_\_\_\_

Signature: \_\_\_\_\_

Tick off only once

- My\* genetic data may only be used for my own treatment and for purposes that are directly related to my treatment.
- I have previously stated that my\* genetic data may only be used for my own treatment and for purposes directly related to my treatment. I now allow them to be used for other purposes permitted under applicable Danish law.

The form is sent to: Sundhedsdatastyrelsen, Vævsanvendelsesregisteret, Ørestads Boulevard 5, 2300 Copenhagen S  
You will receive a receipt for your digital mail on [www.borger.dk](http://www.borger.dk)

\*Notice that if the comprehensive genetic analysis was performed in relation to prenatal testing, then "your genetic information" refers to both the genetic information of the pregnant woman and the fetus.