

Your participation is important!

Patient information on the RaraSwed quality register

What is RaraSwed?

This is a national quality register that makes it possible to monitor and develop care and treatment for you and other patients in the same situation. It is helping to create a coherent national structure for rare health conditions. Your participation will influence and enhance healthcare knowledge.

What information is recorded?

The information recorded includes personal data, healthcare contacts, diagnoses, symptoms and test results.

The data may be collected from your medical records, from you personally or from healthcare professionals.

Your registered data may only be used for:

- developing and ensuring the quality of care
- producing statistics
- healthcare research.

Data publication

Approval must always be given by the Ethical Review Board (Etikprövningsnämnden, EPN) when data from the register is needed for research studies.

When the data is published, it will not be possible to identify you.

and the results will be presented at group level. This means it is not possible to identify individuals on the basis of the data.

Privacy and security

Your data is subject to confidentiality and is therefore treated in the same way as your medical records.

Only authorised personnel are allowed to access your data. Your registered data is protected by means of encryption, secure login and a logging system.

This checks that there has been no unauthorised access to your data.

Your rights

- Your participation is voluntary.
- You can ask for your data to be removed from the register at any time without affecting the care you receive.
- You always have the right to know what data has been recorded.
- You can ask for your data to be corrected if it is incorrect or missing.
- You can get information about the time at which your data was accessed, and at which health centre.
- You are entitled to compensation if your data is processed in violation of the General Data Protection Regulation (GDPR).
- You have the right to know what personal data relating to you has been recorded in the quality register (what is known as a register extract).

If you would like further information or would like your data to be deleted, please see:

www.cdsamverkan.se



Or contact the CSD (Centre for Rare Diagnoses) for your healthcare region: the address can be found on the website

You can also consult:

Data Protection Officer for Region Skåne

Region Skåne

SE-291 89 Kristianstad

Central switchboard: 044 309 30 00

region@skane.se