

PIDcare

**National Quality Register +
Support in Individual Care**

A National Quality Register and support
in individual care of patients with
primary immune deficiency and/or
increased susceptibility to infections

**–Would you like to participate?
Your contribution helps to
improve health care!**



PIDcare

Together we will improve health care!

We constantly strive to develop and improve the quality of care to ensure optimal treatment results and to deliver high-quality patient experiences. The national quality register makes it possible to monitor and improve your care, as well as the care of other patients with primary immunodeficiencies.

Improvement can only be achieved if the majority of patients participate in the register, as this makes it possible to compare results across immunodeficiency clinics in Sweden. Data in the register provide a unique opportunity to analyse what treatment methods, therapies, drugs and products lead to good results, and which ones should no longer be used.

Your doctor and nurse will also use the register to plan, monitor and evaluate your individual care.

Your Contribution

By consenting to enter your data in the register you contribute to improving health care. The information registered is social security number, name, address, telephone number, hospital visits, diagnosis, treatment, infection diary, number of infections, results of blood tests and physical examination. In reports from the registries, results will be presented at group level in order to ensure that your identity is not revealed.

Please visit www.pidcare.se for updated information and downloadable files, including application forms.

Handling of Information

Information will be collected directly from you and from your medical records. The data is only used for specific purposes:

- To develop and ensure the quality of health care
- For statistical purposes
- For research in health care

Data relevant for the above purposes may only be released after confidentiality and ethics approval.

- Planning, monitoring and evaluation of individual care

Only your health care provider has access to your personal data.

Data which is permitted to be released from the register can be transferred electronically. Use of data from the register in research studies always requires approval from a research ethical review board.

If your personal information is to be used for research, you will be asked to consent to participate in the study. Participation in research is always voluntary and should you choose not to participate this will in no way affect your care.

Confidentiality

Your data is protected by the Swedish Public Access to Information and Secrecy Act. This means that personal information may be disclosed only if it is clear that individual patients or people close to them will suffer no harm.

Security

Your data is protected against unauthorized access. Specific requirements ensure that only those who need the information for work purposes have access to it. A control system is used to check that no unauthorized person has obtained access to your data. The information will be protected through encryption, and a secure log-in is required in order to access the registry. It is never possible to identify specific individuals in presentations, statistics or research reports.

Access

Health-care providers have access only to the data they submit to the register. For practical purposes, employees who administer the register do have access to the data.

Deletion

All personal information will be removed when no longer needed for developing and ensuring the quality of health care, or for planning, monitoring and evaluating individual care.

Consent

Written consent is required to register your data in PIDcare. It is possible to consent only to the recording of data for administrative purposes, i.e. social security number, name, address, diagnosis, possible treatment and care planning.

Your Rights

- Participation in the registry is voluntary and does not affect the care you receive. If you decide that you no longer want your information to be recorded, please inform your health-care provider.
- You are entitled to have your data removed from the registry at any time without explaining why.
- You are entitled to receive information about your own personal data in the registry, as well as who has accessed your data and when they did so.
- If your data is used in contravention of the Swedish Data Protection Act, you have the right to claim for damages.
- You may request correction of your data if it is used in contravention of the Swedish Data Protection Act, or if your data is incorrect

Once a year you have the right to know what information has been recorded about you (a register transcript). An application for the transcript must be made in writing, signed and sent to the data controller at the National Quality Register PIDcare. The transcript is free of charge.

Contact Information

If you want more information about PIDcare, please visit www.pidcare.se, where you can also download a brochure and forms.

You can also contact your health-care provider:

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If you would like any of the following, please contact the controller of personal data:

- A register transcript (free of charge once a year upon written request)
- To remove your data from the register
- To receive information about who has had access to your data

Address:

Centralt personuppgiftsansvarig
Landstingsstyrelsen
Landstinget i Jönköpings län
Box 1024
551 11 Jönköping

Your Notes

A series of horizontal dashed lines for writing notes.

PIDcare

Is supported by:



www.pio.nu

The Swedish Patient Organisation



**SVERIGES IMMUNBRISTSJUKSKÖTERSKORS
INTRESSEFÖRENING**

www.sissi.nu

Swedish Nurses' Association for Primary Immunodeficiencies

SLIPI

**Sveriges Läkares Intresseförening
för Primär Immunbrist**

www.slipi.nu

Swedish Physicians' Association for Primary Immunodeficiencies



www.skl.se



NATIONELLA KVALITETSREGISTER

www.kvalitetsregister.se

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