

## Do you want to help improve healthcare?

### What is a national quality register?

A quality register is a system for monitoring and developing collated information about your health/your child's health. You/your child can be included in one or more quality registers. The aim of a quality register is that the collated information should be used to improve health and medical care, promote health and prevent ill-health for all children. Health and medical care professionals can monitor and see changes in children's health over time, at national, regional and local levels, and can compare different ways of working and treatment methods. It is extremely important that as many people as possible contribute towards the quality register, since this increases the reliability of the results and evaluation. The results will be used in ongoing operational improvement measures, to achieve a consistent standard of services and healthcare in Sweden.

### Registering information

The information about you/your child that is collated and registered can include your civic registration number, instances of healthcare contact, information about your health and medical treatment methods. It can also include information from a survey that you have responded to about your health and wellbeing, and how various everyday situations work for you, such as responses to an ongoing treatment method. This information can only be used to I) develop and safeguard the quality of healthcare, II) devise statistics, and III) carry out research within health and medical care. After ethical examination and a thorough review by the quality register's steering group, summaries of information from the register – at group level, so that individual children cannot be identified – may be used for research with the aim of improving the quality of healthcare.

### Confidentiality

Your information/your child's information is protected by health and medical care confidentiality under the Swedish Public Access to Information and Secrecy Act. Information that is issued always undergoes a confidentiality review, to ensure that neither you/your child nor a member of your family will be disadvantaged if this information is issued. It is not possible to identify information about you/your child as an individual from the summaries that are compiled at group level. If information about you/your child is used for research, you will be contacted and participation is voluntary. Approval by an ethics review board is always required for research studies.

### Security

Your information/your child's information is protected against unauthorised access. Specific requirements ensure that only those who need the information have access to it. A systematic check is carried out to ensure that I) no unauthorised party has obtained access to the information, II) the information will be protected through encryption, and III) a secure log-in is required in order to access the information.

### Access

Care providers can access the information that they submit to the register. No other care provider has access to this information. Those who administer the register centrally can and may access your child's information.

### Deletion

Your information will be removed when it is no longer needed for developing and safeguarding the quality of healthcare. For certain registers, the relevant archiving authority may decide that your information should be saved until further notice for historical, statistical or scientific purposes.

### Your rights/your child's rights

You will receive oral and/or written information to confirm that participation in the register is voluntary and does not affect the services and the care that you/your child receive. *If you do not want your information/your child's information to be registered, please inform the care provider* (see the link on the right-hand side of the website for the relevant register).

You can change your mind at any time and have your information/your child's information deleted from the register. You are also entitled to damages if your information/your child's information is used in

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contravention of the Swedish Data Protection Act, and are entitled to ask for information to be corrected. You are also entitled to receive information about what access there has been to your information/your child's information. You are entitled to find out what information has been registered about you/your child (a "register extract") once a year, free of charge. Any such application should be made in writing, signed and sent to the contact person for the national quality register. **If you have any questions, please see the contact details for the relevant quality register at [www.lj.se/barnochvuxenkvalitetsregister](http://www.lj.se/barnochvuxenkvalitetsregister) under "Kontakt/Logga in".**