# Patient information

## BORIS, the Childhood Obesity Registry in Sweden

In order to develop and guarantee the quality of care for childhood obesity, *CARE PROVIDER* wishes to report information about your child to the Childhood Obesity Register in Sweden (BORIS). Region Stockholm is the central body responsible for personal data for BORIS. CARE PROVIDER is the party responsible for personal data in connection with information about your child being collected and registered in BORIS.

If you do not want information about your child to be registered in BORIS, please contact ……………. *(representative of CARE PROVIDER)*

**You’re contributing to better care!**

By becoming involved in BORIS, your child is contributing to improving care for childhood obesity. The information is used to compare care of childhood obesity between different hospitals and paediatric wards all over Sweden. We will then use the results in our work to improve care. The quality register contributes to new knowledge about how we should treat childhood obesity, and the more who take part, the more reliable the results will be.

**Information that will be registered**

In order to develop and guarantee the quality of care for childhood obesity, we want to register details of your child’s date of birth, his/her care contacts with us, treatment and test results.

**How the information about your child is handled**

Information about your child is collected from the child’s patient records and from you yourselves. The information in the quality register may only be used to develop and guarantee the quality of care for childhood obesity, to produce statistics and for research. The information may also, following a confidentiality check, be issued to someone who will use the information for one of these three purposes. If information may be issued from BORIS, it can take place electronically.

*Confidentiality*

A child’s information is protected by the provisions on health and medical confidentiality in the Swedish Public Access to Information and Secrecy Act. This means, as a general rule, that information about your child may only be issued from BORIS if it is clear that neither your child nor you as parents/guardians will suffer any detrimental effects if the information is disclosed.

*Security*

Your children’s information in BORIS is protected against unauthorised access. There are special requirements for security measures that mean, among other things, that only a person who needs the information may have access to it, that a check must be performed to ensure that no unauthorised person has accessed the information, that the information must be protected by means of encryption and that logging in in order to access the information may only take place in a secure way.

*Access*   
As the reporting care provider, CARE PROVIDER has direct access to the information registered in BORIS. No other care provider has direct access to this information. As the party responsible for the register, Region Stockholm may have access to information about your child.

*Screening*

Information about your child is deleted when it is no longer needed to develop and guarantee the quality of care for childhood obesity.

**Rights**

You have the right at any time to request that information about your child be removed from BORIS. You also have the right to obtain information about any access to your child’s information that has taken place. You also have the right to damages if the personal information is handled in a way that is in breach of the Swedish Personal Data Act or the Swedish Patient Data Act. If personal information has been handled in a way that is in breach of the Swedish Personal Data Act, you have the right to demand a correction of the information. You have the right once a year to find out which personal information is registered about your child (register extract). This is free of charge. Such an application must be made in writing, signed by both parents/guardians and submitted to the contact person below.

If you would like more information about BORIS, please contact:

……………………………………………………………………………….. *(representative of CARE PROVIDER)*

If you would like a register extract for your child, please send your written request to:

Pernilla Danielsson Liljeqvist

Karolinska Universitetssjukhuset Huddinge/Karolinska Institutet

Blickagången 6A, Novum

141 57 Huddinge

(representative of Region Stockholm)

If you want your child’s information to be deleted from the register, please contact:

Pernilla Danielsson Liljeqvist  
pernilla.danielsson-liljeqvist@regionstockholm.se  
08-585 874 23

(representative of Region Stockholm)