Swedish National Celiac Disease Register

SND-ID: ext0139-1.

Associated documentation

Do you want to use the register, in English.pdf *(67.66 KB)*

How to report, in English.pdf *(62.14 KB)*

Hur sker rapportering, Svenska.pdf *(71.8 KB)*

Infobrev föräldrar English and Swedish.pdf *(160.38 KB)*

Infobrev till föräldrer, Svenska.pdf *(94.19 KB)*

Infobrev, förälder, personnr Nationellt register, Svenska.pdf *(55.49 KB)*

Information to parent, in English.pdf *(109.44 KB)*

Information, parent, IDnr National register, in English.pdf *(40.71 KB)*

Vill du nyttja registret, Svenska.pdf *(76.17 KB)*

Creator/Principal investigator(s)

Anneli Ivarsson - Umeå University, Department of Epidemiology and Global Health

Research principal

Umeå University - Department of Epidemiology and Global Health

Description

Celiac disease, also known as gluten intolerance, is a permanent sensitivity to gluten which is found in wheat, rye and barley. The cause of celiac disease is still unclear but we know that both heredity and environment play a role. In Sweden, celiac disease more common than in many other countries. It is crucial to find out why this is so and if we can reduce the incidence of celiac disease by changing lifestyle in any way. We can increase the awareness of celiac disease by following the pattern of the disease across the country as well as through other research.

Since 1998 Sweden has had a unique incidence register for celiac disease in Sweden. The register was started through the initiative of the Swedish Pediatric Association (Barnläkarföreingen/BLF). In 1996 the Board offered new guidance on the introduction of gluten to the infant diet and the registry is an important part of quality assurance related to this.

The registry is administered, via the BLF's Gastroenterology and Nutrition section and, at the Department of Epidemiology and Gublic Health, Umeå University. This includes, among other things, planning and ongoing work with the registry to regularly send back reports to the participating units and to compile the incidence trends. The register’s steering group consists of three pediatricians; one representative of the Section’s Board, the celiac disease working group on celiac disease, and the registry management.

The registry has ethical approval and complies with the Personal Data Act and privacy regulations. Under this Act, children and parents have the right to obtain extracts from the register.

Purpose:

Through a nationwide registry for celiac disease in Swedish children the trend of the incidence of celiac disease can be followed and changes over time and geographical differences can be analyzed. The registry shall form the basis of other studies, for example disease etiology, opportunities for prevention, diagnosis, and long-term consequences with a goal to providing greater knowledge about celiac disease.

Data contains personal data

No

Unit of analysis

Individual

Population

All the country's pediatric clinics and clinics, that perform intestinal biopsies, participate in reporting to the register. All clinics report all new cases of probable celiac disease *in children aged 0-17.99 years.

Time Method

Longitudinal

Sampling procedure

Non-probability
All of the country's pediatric clinics and clinics, that perform intestinal biopsies, participate in reporting to the register. Each participating unit appoints a contact person to get information and pass it on to those concerned. Employees at participating pediatric clinics and clinics inform children and parents about the registry orally and in writing, reporting within one month of each new probable celiac disease case in children aged 0-17.99 years old and with continued updates with results from further investigations.

Reporting of new cases is based on a standardized form including personal identity number, sex, place of residence and basis for diagnosis, i.e. symptoms, serological markers, HLA-DQ2/DQ8, and small intestinal biopsy mucosal evaluation.

Time period(s) investigated

1998 – Ongoing

Data format / data structure

Numeric

Data collection 1

- Mode of collection: Physical measurements and tests
- Time period(s) for data collection: 1998–ongoing
- Source of the data: Registers/Records/Accounts: Medical/Clinical, Registers/Records/Accounts

Geographic spread

Geographic description: Sverige

Responsible department/unit

Department of Epidemiology and Global Health

Ethics Review

Umeå - Ref. 101-U2496-04

Research area

Medical and health sciences (Standard för svensk indelning av forskningsämnen 2011)

Basic medicine (Standard för svensk indelning av forskningsämnen 2011)

Gastroenterology and hepatology (Standard för svensk indelning av forskningsämnen 2011)

Public health, global health, social medicine and epidemiology (Standard för svensk indelning av forskningsämnen 2011)

Health (CESSDA Topic Classification)

Diet and nutrition (CESSDA Topic Classification)

Specific diseases, disorders and medical conditions (CESSDA Topic Classification)

Keywords

Primary prevention, Registries, Celiac disease, Glutens, Celiac, Wheat, Rye, Grain, National register, Infant feeding recommendations, Swedish pediatric association, Nutrition

Publications

Grodzinsky E, Ivarsson A, Juto P, Olcén P, Fälth- Magnusson K, Persson LÅ, Hernell O. New automated immunoassay measuring Immunoglobulin A anti-gliadin antibodies for prediction of celiac disease in childhood. Clin Diag Lab Immunol 2001;8:564-570.
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Namatovu F, Sandström O, Olsson C, Lindkvist M, Ivarsson A. Celiac disease risk varies between birth cohorts, generating hypotheses about causality: evidence from 36 years of population-based follow-up. BMC Gastroenterology 2014 14:59 doi:10.1186/1471-230X-14-59.
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Accessibility level

Access to data through an external actor
Access to data is restricted

Contact for questions about the data

Anneli Ivarsson

anneli.ivarsson@umu.se

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