



Data Resource Profile

Data Resource Profile: The Nordic Obesity Surgery Cohort (NordOSCo)

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Data resource basics

The rapidly increasing prevalence of obesity and its negative impact on morbidity and mortality has turned obesity into one of the greatest public health challenges globally. Bariatric surgery is an increasingly common treatment of obesity and is more effective than non-surgical treatment alternatives in achieving substantial and long-lasting weight loss in severely obese individuals.¹ Studies have shown that bariatric surgery leads to reduced overall mortality² and remission of obesity-associated comorbidities such as cardiovascular diseases and diabetes.³ Short-term outcomes of bariatric surgery have been vastly documented in scientific literature, but there is limited knowledge on the long-term impact of bariatric surgery on obesity-related diseases.

The Nordic Obesity Surgery Cohort (NordOSCo) was established through a collaborative effort between researchers from the Karolinska Institutet (Sweden), University of Copenhagen (Denmark), University of Tampere (Finland),

University of Iceland (Iceland) and Norwegian University of Science and Technology (Norway). The main aim is to evaluate long-term and rare outcomes in patients who have undergone bariatric surgery, and to compare outcomes with obese patients who have not undergone such surgery. The cohort includes all individuals who have ever received a diagnosis of obesity in a hospital setting from any of the five Nordic countries (i.e. Denmark, Finland, Iceland, Norway and Sweden). The overall inclusion period is from 1964 to 2012, with some variation between countries depending on data availability: 1976 to 2011 in Denmark, 1968 to 2012 in Finland, 1999 to 2012 in Iceland, 2007 to 2011 in Norway and 1964 to 2012 in Sweden. Populations in the Nordic countries are relatively similar in sociodemographic characteristics, genetic background and cultural traditions and norms. Additionally, the health care and social systems are comparable between the countries. Thus, combining data from all Nordic countries offers opportunities to increase sample size without introducing substantial heterogeneity.

The NordOSCo contains 506 826 individuals with a diagnosis of obesity, of whom 57 283 (11.3%) have undergone bariatric surgery. Characteristics of the cohort members at study entry are presented in Table 1. Most individuals entered the cohort from year 2000 onwards. Denmark contributed with the largest number of individuals to the cohort, whereas many of the cohort members who had undergone bariatric surgery were from Sweden. Participants with a history of bariatric surgery were overall younger at study entry and comprised of a larger proportion of females compared with the entire cohort.

Data collected

Source data

All data in the NordOSCo were collected from national health and population registries in the five Nordic countries: the Patient Registry, the Cancer Registry, the Causes

Table 1. Characteristics of participants in the Nordic Obesity Surgery Cohort (NordOSCo)

	Complete cohort	Bariatric surgery (11.3%)
Number of participants	506826 (100)	57283 (100)
Person-time, years	3597897	313036
Age at entry, years (%)		
< 25	59810 (11.8)	14628 (25.6)
25–34	91287 (18.0)	18527 (32.3)
35–44	88717 (17.5)	12537 (21.9)
45–54	88953 (17.6)	4675 (8.2)
55–64	87718 (17.3)	6725 (11.7)
≥ 60	90341 (17.8)	191 (0.3)
Age at surgery, years (%)		
< 25	NA	12734 (22.2)
25–34	NA	19412 (33.9)
35–44	NA	14429 (25.2)
45–54	NA	6462 (11.3)
55–64	NA	3864 (6.7)
≥ 65	NA	382 (0.7)
Calendar period at entry		
< 1990	78290 (15.4)	4015 (7.0)
1990–1999	48474 (9.6)	8128 (14.2)
2000–2004	75101 (14.8)	7976 (13.9)
2005–2009	185616 (36.6)	23649 (41.3)
≥ 2010	119345 (23.6)	13515 (23.6)
Sex		
Male	165023 (32.6)	14193 (24.8)
Female	341803 (67.4)	43090 (75.2)
Country		
Denmark	219488 (43.3)	11916 (20.8)
Finland	77454 (15.3)	4424 (7.7)
Iceland	14024 (2.8)	624 (1.1)
Norway	34095 (6.7)	5510 (9.6)
Sweden	161765 (31.9)	34809 (60.8)

of Death Registry and the Registry of the Total Population. All five countries have maintained high quality, nationwide complete registries for several decades for administrative purposes that are similar in design and content, and data from different registers can be linked on an individual basis by means of a personal identity code.⁴ Consequently, virtually all publicly financed bariatric surgical procedures performed in the Nordic countries, since their introduction in the 1980s, are documented in the registries. This enables individual follow-up for, among others, morbidity and mortality outcomes. Included registries are summarized in this profile, but detailed description can be found elsewhere.^{5–10} Figure 1 illustrates the variables obtained from each registry and included in the NordOSCo.

In short, individuals with a diagnosis of obesity were identified from the patient registries that record all hospital care episodes (inpatient care, outpatient specialized care and day surgery), including admission and discharge dates, procedure codes (including codes for bariatric surgery) and discharge diagnoses (including obesity), according to the International Statistical Classification of Diseases and Related Health Problems. For example, in the case of bariatric surgery, all hospital care episodes after surgery (including readmissions) are accessible from the patient registry until the end of study period, regardless of which hospital the patients visited after surgery. Additionally, the patient registries were used to obtain information on comorbidities. The patient registries were initiated in 1964 in Sweden, 1967 in Finland, 1977 in Denmark and 1999 in Iceland; the Norwegian registry first included personal identifiers that are linkable to the other registries in 2007. Validation studies of the patient registries show overall high completeness and accuracy. The positive predictive value of a correct diagnosis in the Danish Patient Register ranged from 73% to 89% when considering the primary diagnosis code alone, and from 81% to 94% for primary and two secondary diagnoses. Orthopaedic diagnoses had highest validity and medical diagnoses had the lowest validity.¹¹ Similarly, the positive predictive value for common diagnoses ranged from 75% to 99% in the Finnish Patient Registry and from 85% to 95% in the Swedish Patient Registry.^{10,12} For the purpose of the NordOSCo, we considered both primary and secondary diagnoses for assessing obesity and comorbidities. A validation study from our group of bariatric surgery registration in the Swedish Patient Registry found high accuracy and completeness, i.e. 97% concordance with operation charts.¹³

The cancer registries contain information on all malignant tumours, such as date of diagnosis, topography and morphology, for the entire study period of the NordOSCo. Validation studies of the cancer registries have found high

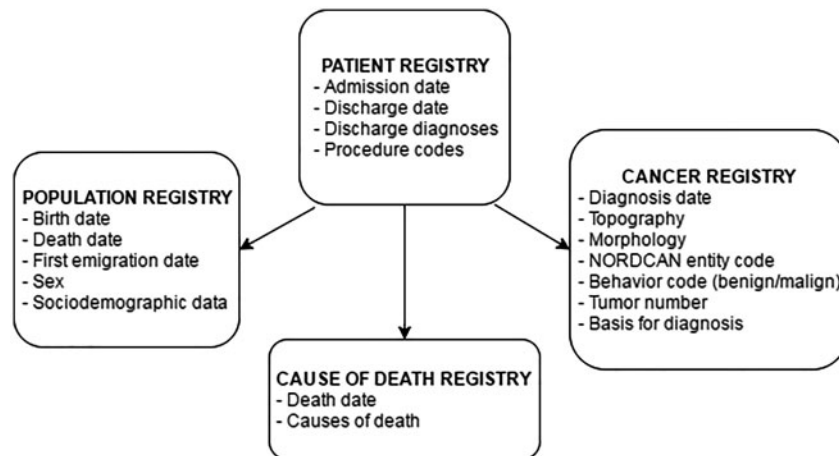


Figure 1. Registries from which data for the Nordic Obesity Surgery Cohort (NordOSCo) were retrieved and the variables included.

completeness and accuracy. The Icelandic Cancer Register was 99.2% complete and 96.4% of the cases were morphologically verified.¹⁴ The Norwegian Cancer Register was 98.8% complete and 93.8% of all tumours were morphologically verified.¹⁵ The Finnish Cancer Registry includes around 99% of all cancers;¹⁶ 93.4% of them were morphologically verified in 2008–09.¹⁷ Morphological verifications were available for 89% of the tumours in the Danish Cancer Registry and 99% in the Swedish Cancer Registry.^{18,19}

The causes of death registries provide data on dates and causes of death for the entire study period of NordOSCo. Some countries also include deaths that occurred abroad. There are few validation studies on the causes of death registries, and available studies have shown moderate accuracy. Autopsy rates are generally low, and a previous study found that 30% of the causes of death were changed after an autopsy had been performed.²⁰ The completeness is higher and is reported to be 100% in the Swedish Causes of Death Registry.²¹ For the purpose of the NordOSCo, the causes of death registries serve primarily as the source of information on date of death, for which they have high completeness and accuracy.

The registries of the total population contain information on sociodemographic variables, dates of birth and death, and emigration and immigration status. In the Swedish Population Registry, all births and deaths, and almost all immigrations (95%) and emigrations (91%), are recorded within 30 days.⁹

Because some demographic variables, i.e. birth date, death date and sex, are available from several registries in the NordOSCo, we combined the registries to obtain the most complete demographic data. As only month and year of birth and death were accessible from Iceland and Norway due to data handling regulations, the dates of

birth and death were imputed to the 15th day of each month in these countries.

Dataset production

Obesity was identified from the diagnosis codes 287 in the International Statistical Classification of Diseases and Related Health Problems version 7 (ICD-7): 277 in ICD-8, 278 A in ICD-9 or E66 in ICD-10. Cohort members who underwent bariatric surgery during the study period (and were considered exposed) were ascertained from procedure codes in the same patient registries. We used the following operating codes, based on NOMESCO Classification of Surgical Procedures, to identify individuals who had undergone bariatric surgery: JDF00–01, JDF10–11, JDF20–21, JDF 96–97, JFD 03–04, JFD20 and JFD96. The NOMESCO classification was introduced in Denmark in 1996, in Finland, Norway and Sweden in 1997 and in Iceland in 1999.²² Country-specific procedure codes were in use before the NOMESCO classification. Sweden (codes 4750–4753 and 4759) and Finland (codes 6548 and 6559) also contributed with individuals who had undergone bariatric surgery before the NOMESCO classification came into use.

Individual-level data on the cohort members were extracted from the registries in each country during year 2013, and data were obtained from all available years at the time of data extraction, i.e. all hospital care episodes in the patient registries, all tumours in the cancer registries, all deaths in the cause of death registries and all sociodemographic information and immigration or emigration registered in the registries of the total population. Participants entered the cohort at the date of their first obesity diagnosis if aged 18 or above. Individuals who

obtained a diagnosis of obesity before age 18 entered the cohort at their 18th birth date. Person-time accumulated from the date of obesity diagnosis until date of bariatric surgery, date of death, date of emigration or end of study period (end dates) was allocated as unexposed. Exposed person-time was accrued from the date of bariatric surgery until date of death, date of emigration or end of study period. A majority (82.0%) of the bariatric surgery patients entered the cohort before the date of their first bariatric surgery. Time between first obesity diagnosis and first surgery was 0.7 years (259 days) median and 2.6 years mean (standard deviation 5.0 years). Figure 2 illustrates the inclusion and exclusion of individuals throughout the data management process. Individuals whose end date occurred before age 18 were excluded from the study, as well as individuals who emigrated before their first registered obesity diagnosis and individuals who lacked information on birth dates.

Ethical clearance and funding sources

Ethical approval and data retrieval permissions were sought and approved by the responsible agencies in each country. The names of the agencies and permissions are presented in Supplementary Table 1, available as Supplementary data at *IJE* online. Ethical approvals were

not required for register-based research in Denmark and Finland. Register-based research is also exempt from informed consent from participants in all Nordic countries. In each country, individuals in the registries were linked by the relevant agencies, using the personal identity code.⁴ The country-specific cohorts were retrieved and checked for inconsistencies. Data from each country were then sent to Statistics Denmark for merging, data management and storage. Access to data on a server maintained by Statistics Denmark was obtained for the researchers involved in the data management of the NordOSCo through a safe and coded distant connection established via the Danish collaborators.

Data resource use

Our collaborative research group is particularly interested in the impact of bariatric surgery on cancer risk, but the NordOSCo can be used to study a vast number of short- and long-term outcomes associated with bariatric surgery. Thus far, three studies have been completed assessing morbidity associated with bariatric surgery in the Swedish participants of NordOSCo. As obesity is associated with oesophageal adenocarcinoma, one study examined the risk of oesophageal cancer after weight loss from bariatric surgery, and found no protective effect of this surgery.²³

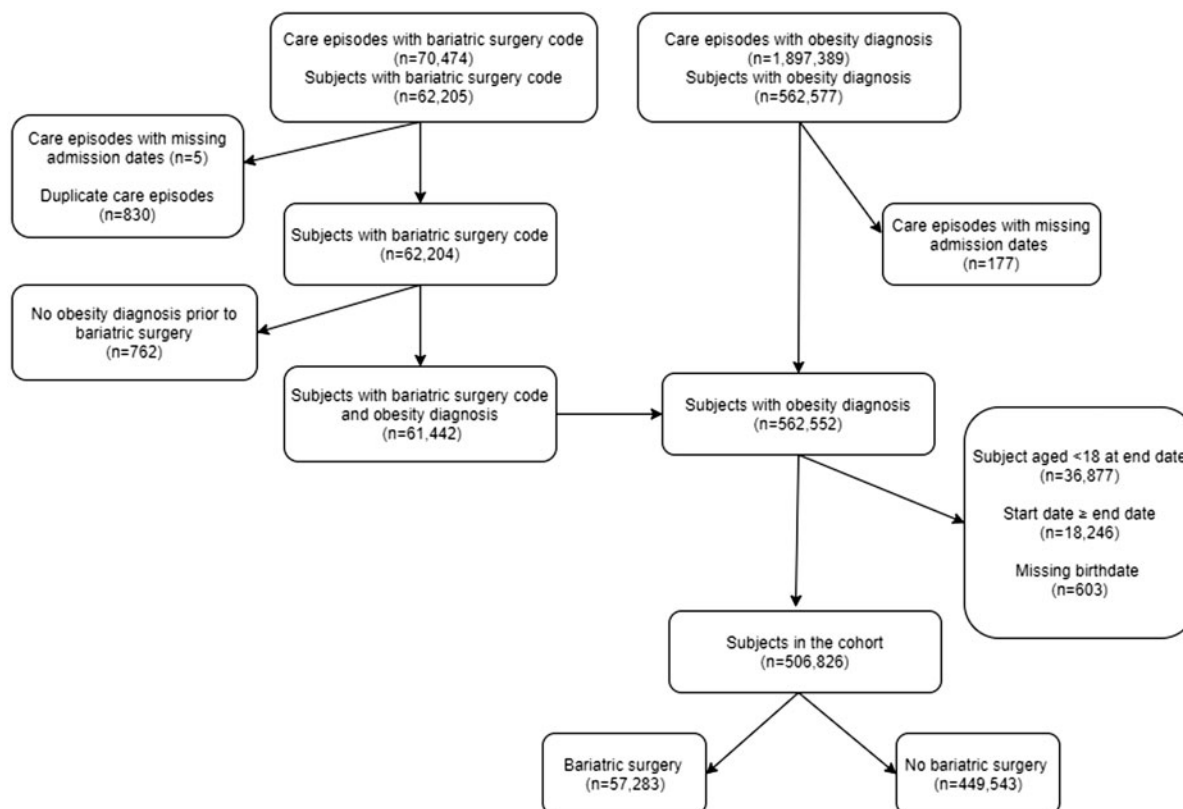


Figure 2. Flowchart illustrating the selection of participant to the Nordic Obesity Surgery Cohort (NordOSCo).

Another study assessed the association between bariatric surgery and prognosis of colorectal cancer, as some previous studies have indicated an association between bariatric surgery and increased risk of colorectal cancer. Individuals with and without a history of bariatric surgery, and who have been diagnosed with colorectal cancer, were followed up for cancer-specific mortality. The study found a significantly poorer prognosis in rectal cancer patients with a history of bariatric surgery compared with obese controls, whereas no such association was observed for colon cancer.²⁴ A third study evaluated predictive factors for developing marginal ulcers after bariatric surgery, and identified diabetes and a history of peptic ulcer as risk factors.²⁵

The NordOSCo can also be used to evaluate changes in trends of bariatric surgery in the Nordic countries over time and their relation to policy changes. Bariatric surgery was mainly performed in Sweden during the 1980s and 1990s, and occurred only rarely in the other Nordic countries. A rapid increase in the number of bariatric procedures per 100 000 inhabitants was observed in all Nordic countries during the 2000s, with Sweden and Denmark in the lead on the absolute number of bariatric surgeries performed, whereas Iceland had a high volume of bariatric procedures relative to its population size (Figure 3). The drop in the number of bariatric surgeries in three countries during the last year of the study period could be explained by, for example, delayed data reporting if registrations of hospital care episodes for the most recent year were not complete at the time of data extraction. In Denmark however, change in eligibility criteria for bariatric surgery on 1 January 2011 likely explains some of the drop in the rate of bariatric surgery from 2010 to 2011. According to the new regulations, the body mass index (BMI) threshold for publicly financed bariatric surgeries was increased from 40 kg/m² to 50 kg/m² in the absence of comorbidity, although the BMI threshold remained unchanged for private health care providers.²⁶ Additionally, private providers offering bariatric surgery (both private and publicly financed) have become increasingly common in the Nordic countries, shifting more of the surgeries from public to private providers, which might influence rates of reporting to the patient registries.

The descriptive data also illustrate the changes in bariatric surgical techniques over time. Bariatric surgical procedures can be divided into three main groups according to mechanism of action: restrictive, malabsorptive or mixed restrictive and malabsorptive.²⁷ The predominant restrictive procedures have been vertical banded gastroplasty and adjustable gastric banding. Only recently, and outside the time period of NordOSCo, the use of the gastric sleeve has emerged. Malabsorptive procedures include intestinal

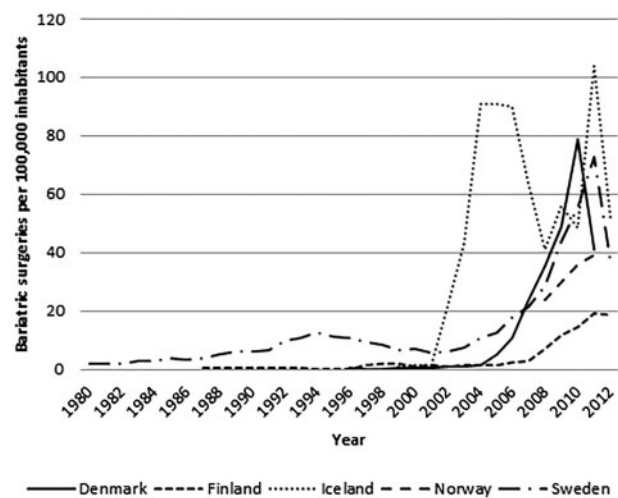


Figure 3. Number of bariatric surgeries per 100,000 inhabitants by country and year in the Nordic Obesity Surgery Cohort (NordOSCo).

bypass, but are unusual. Gastric bypass is the most common mixed restrictive and malabsorptive surgery. Restrictive bariatric surgeries dominated the scene in the 1980s and 1990s, but gastric bypass became the predominant surgical procedure from 2000s onwards and is the treatment of choice for most patients and surgeons in the Nordic countries, outweighing all other bariatric surgical procedures combined in the entire cohort (Figure 4).

Strengths and weaknesses

Strengths of the NordOSCo include the large sample size, containing almost all cases of bariatric surgery and all individuals with a diagnosis of obesity in the nationwide patient registries from the five Nordic countries, from as far back as register data are available. The population-based design and the completeness of the registries reduce the risk of selection bias and differential follow-up. Additionally, recall bias is minimized as data in the registries have been collected prospectively for administrative purposes, and no contact has been made with the subjects themselves. Any misclassification is likely to be non-differential, as the data collection is uniform for all subjects and independent of the exposure or outcome status.

The cohort contains data on a large number of variables that enable research on a vast range of study objectives. The registries are updated on a monthly or yearly basis, and the cohort can be linked repeatedly to these registries to obtain additional data from later time periods as they become available. Overall, assessments of the registry data underlying NordOSCo have found the data to be reliable,^{5–9,28} and a validation study of bariatric surgery codes using Swedish data indicated that misclassification of bariatric surgery in the Swedish Patient Registry is rare.¹³

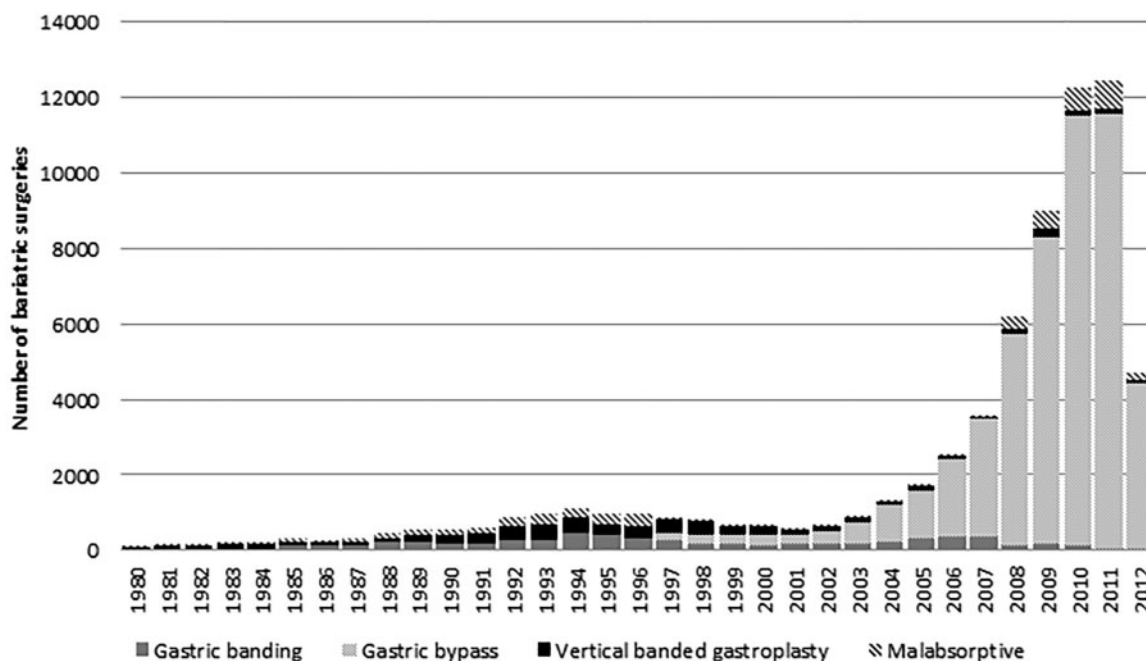


Figure 4. Number of bariatric surgeries in the Nordic Obesity Surgery Cohort (NordOSCo), by calendar period and type of procedure.

Information contained in the current dataset can also be expanded by linking the existing cohort to other registries, e.g. multi-generation registries, birth registries, prescription registries and the conscription registries. Additionally, the cohort can be merged with primary care registries and disease-specific registries ('clinical quality registries') that contain information specifically collected for research and quality improvement purposes of certain diagnoses and procedures.²⁹ For example, to obtain additional pre- and post-surgical information that is not available from the patient registries (e.g. BMI, laboratory results, complications, quality of life measures) it is possible to link the cohort to the Scandinavian Obesity Surgery Registry (SOREg) which is a clinical quality registry providing detailed data on individuals who have undergone bariatric surgery in Sweden since 2007.³⁰

One of the limitations of the NordOSCo lies with the individuals who have no history of bariatric surgery. Although the cohort contains a large number of non-operated obese individuals as comparison (considered as non-exposed), they were identified based on having an obesity diagnosis in the patient registries. Thus, only obese individuals who have been in contact with inpatient or outpatient specialized care were included. Furthermore, the date of obesity diagnosis is not a precise measure of when the subject first became obese. These drawbacks might be partially remedied by adjustment or stratification by age, sex, year of diagnosis or comorbidities in the analyses. Another limitation is the lack of data on BMI and lifestyle

factors that might influence associations between bariatric surgery and outcomes of interest. Data that are typically collected through surveys, such as self-rated health status, could be linked to our cohort, but they would only be available for a small proportion of the cohort. However, due to the large size of the cohort it may be possible to limit the study population to subsamples for which data are available and still achieve sufficient sample size for robust analyses.

Data resource access

We invite collaboration with researchers who are interested in obesity, bariatric surgery and related subjects where the NordOSCo can be a valuable source of data. All data presented in this article are stored on a server maintained by Statistics Denmark. Data access is granted according to the regulations of the agencies in each country and cannot be directly exported from the server platform unless in aggregated format. The server at Statistics Denmark has been described in previous publications.^{31,32} Through an individual double log-on procedure, accredited researchers may enter the server environment where the data are located in a project-specific folder. Conventional statistical packages such as STATA, SAS, R and SPSS are available through the server for data management and statistical analysis. All personal identity codes are anonymized and replaced with arbitrary numbers. A key between the personal identity code and the arbitrary number is stored

in the national data agencies in the respective country, and can be used for later updates of NordOSCo but are not accessible to the researchers. There are currently no plans for updating the data resource, but updates with additional years of follow-up or linkage to other registries are possible by means of the key.

Researchers interested in collaboration are welcome to contact Professor Jesper Lagergren [jesper.lagergren@ki.se], principal investigator of the NordOSCo, and the national research collaborators and data owners. Currently, a restricted number of researchers have access to the NordOSCo data, but applications for other researchers can be submitted by the principal investigator and national research collaborators to the necessary agencies for approval.

Profile in a nutshell

- NordOSCo is a Nordic cohort of individuals with obesity, set up to investigate short- and long-term impacts of bariatric surgery on morbidity and mortality.
- The cohort consists of 506 826 individuals with an obesity diagnosis, including 57 283 individuals with a history of bariatric surgery, identified from the Patient Registries of the five Nordic countries (Denmark, Finland, Iceland, Norway and Sweden)
- The study period varies between countries according to data availability at the time of data collection, i.e. 1976 to 2011 in Denmark, 1968 to 2012 in Finland, 1999 to 2012 in Iceland, 2007 to 2011 in Norway and 1964 to 2012 in Sweden.
- Data on sociodemographic characteristics, health care use, diagnoses including detailed information on cancer, and causes of death are available for all individuals in the cohort.
- The data have been collected prospectively and the follow-up of individuals in the cohort is virtually complete.
- Interested research collaborators can contact Professor Jesper Lagergren or the research collaborators in each participating country.

Supplementary Data

Supplementary data are available at *IJE* online.

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