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REVIEW ARTICLE

# Systematic review of tonsil surgery quality registers and introduction of the Nordic Tonsil Surgery Register Collaboration

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## Abstract

**Purpose** Surgical quality registers provide tools to measure and improve the outcome of surgery. International register collaboration creates an opportunity to assess and critically evaluate national practices, and increases the size of available datasets. Even though millions of yearly tonsillectomies and tonsillotomies are performed worldwide, clinical practices are variable and inconsistency of evidence regarding the best clinical practice exists. The need for quality improvement actions is evident. We aimed to systematically investigate the existing tonsil surgery quality registers found in the literature, and to provide a thorough presentation of the planned Nordic Tonsil Surgery Register Collaboration.

**Methods** A systematic literature search of MEDLINE and EMBASE databases (from January 1990 to December 2016) was conducted to identify registers, databases, quality improvement programs or comprehensive audit programs addressing tonsil surgery.

**Results** We identified two active registers and three completed audit programs focusing on tonsil surgery quality registration. Recorded variables were fairly similar, but considerable variation in coverage, number of operations included and length of time period for inclusion was discovered.

**Conclusion** Considering tonsillectomies and tonsillotomies being among the most commonly performed surgical procedures in otorhinolaryngology, it is surprising that only two active registers could be identified. We present a Nordic Tonsil Surgery Register Collaboration—an international tonsil surgery quality register project aiming to provide accurate benchmarks and enhance the quality of tonsil surgery in Denmark, Finland, Norway and Sweden.

**Keywords** Quality assurance · Surgical quality · Tonsillectomy · Tonsillotomy · Registry · Database

## Introduction

The Nordic countries are known for maintaining high-quality health care registers and exploiting them for research, monitoring and development purposes of health care services. All citizens have a unique personal identity code used for all social services, and together with relatively small homogenous population and predominately tax-funded healthcare system the prerequisites for establishing reliable registers are beneficial. In Denmark, Finland, Norway and Sweden

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governmental authorities finance and administer numerous medical quality registers [1–4]. The establishment of national quality registers has been most developed in Sweden, featuring altogether over 100 medical quality registers, of which nine are focused on ear, nose, and throat diseases [1]. Among these the National Tonsil Surgery Register in Sweden (NTSRS) has been operational since 1997 [5].

The history of tonsil surgery dates back to ancient Rome [6] and today tonsillectomies are among the most commonly performed surgical procedures worldwide. Despite tonsil surgery being an established procedure and the fact that more than 10,000 publications can be found on the topic on MEDLINE, large variation exists in clinical practice with respect to demographics in patient selection, application of indications, choice of surgical methods (i.e., tonsillectomy vs. tonsillotomy) and techniques (i.e., cold vs. hot), level of care (outpatient vs. inpatient surgery), postoperative complications (haemorrhage), use of antibiotics, recommendations for pain management, and patient-reported outcome [7]. An inconsistency in evidence for best clinical practice has been concluded by Cochrane and is indeed reflected in the diversity in clinical practice [8–11]. Table 1 presents descriptive data on tonsil surgery in Denmark, Finland, Norway, and Sweden and demonstrates differences regarding the rate of tonsillectomies and tonsillotomies, national guidelines, choice of level of care, and practices regarding tonsillectomy for acute peritonsillar abscess between four Nordic countries.

Ideally the choice of clinical practice should be based on well-designed prospective randomized multi-center studies. In reality, they are challenging to implement due to economic, organizational or practical reasons, and in some cases, randomized studies of treatment protocols can be considered unethical, if a well-established clinical practice based on empirical evidence exists [12]. In addition, due to narrow eligibility criteria and the better than average know-how in the units providing the interventions, the generalizability of the randomized controlled studies may not be optimal. Therefore, observational studies and especially comprehensive register data may provide even more accurate information on outcome in real-life setting [13].

To meet the challenge of inconsistency of evidence regarding the best practices in tonsil surgery, collaborators from Denmark, Finland, Norway, and Sweden established The Nordic Tonsil Surgery Register Collaboration (NTSRC) in 2016. The aim is to build national quality registers based on the Swedish model, with common structure, definitions, and variables enabling comparisons between these countries and increasing the data content available for research, surveillance and quality improvement programs.

The present study aims to systematically investigate the existing tonsil surgery quality registers around the world, and to provide a thorough description of the planned NTSRC.

**Table 1** Descriptive data on tonsil surgery in the four Nordic countries

| | Denmark | Finland | Norway | Sweden |
|---|---|---|---|---|
| Population | 5.7 M | 5.5 M | 5.3 M | 10.0 M |
| Annual number (2014) of | | | | |
| Tonsillectomies[a] [50, 53–55] | 6063 | 7347 | 10004[c] | 7516[d] |
| Tonsillotomies[a] [50, 54, 55] | < 80[b] | 825 | 282 [c] | 6011[d] |
| Day-case surgery (tonsillectomies, %, 2014) [53] | 46.1 | 84.0 | 59.7 | 59.0 |
| National guidelines for indications [56–58] | Yes | Yes | No | Yes |
| National guidelines for postoperative pain management [20] | No | No | No | Yes |
| Practice of quinsy tonsillectomy (Adult patients) [59]<br>"If you decide on a tonsillectomy, how soon after diagnosis of peritonsillar abscess do you attempt to operate?" | 90% of cases operated within 24 h | About 75% of patients operated after a recovery period | About half of the patients operated within 3 days | About 75% of patients operated after a recovery period |

[a]With or without simultaneous adenoidectomy

[b]Exact number of tonsillotomies in Denmark is not available due to limitations of national patient register data

[c]Tonsillectomies and tonsillotomies performed in private practice in Norway are not separately registered. Private practice tonsillotomies are included in the total number of tonsillectomies

[d]Proportions of tonsillectomies and tonsillotomies are calculated based on the Swedish National Tonsil Surgery Register statistics and The Swedish Patient Register data

## Methods of systematic review

A systematic search was conducted according to the recommendations of the Preferred Reporting Items for Systematic Reviews and Meta-analysis (PRISMA) statement [14]. MEDLINE was searched using the Ovid search engine for articles published from January 1990 to December 2016, using keywords and Medical Subject Headings (MeSh) based on the following terms: Registries/Quality Assurance (Health care)/Quality Improvement/Population Surveillance/Databases, Factual/Database management Systems/Outcome and Process Assessment (Health care)/Audit.mp. combined with Tonsillectomy/Tonsil*.mp. The search was supplemented with EMBASE references of the Scopus database using related keywords. All studies with abstract available were included. Language was restricted to Danish, English, Finnish, German, Norwegian and Swedish.

Drolet and Johnson [15] have created a detailed definition for medical data registers (MDR) and outlined five characteristics to meet the definition: (1) mergeable data, (2) standardized dataset, (3) rules for data collection, (4) observations associated over time, and (5) knowledge about patient outcomes. In addition, a register must have an inclusion principle; a characteristic that is common to all patients in a MDR. This definition was used as a basis for inclusion. A single investigator (JR) reviewed the titles and abstracts to identify potentially relevant publications addressing registers, databases, quality assurance programs and comprehensive audit programs fulfilling the definition of MDR, pursuing prospective data recording, and having patient inclusion principle of tonsil surgery. After initial abstract review, full texts of appropriate articles were reviewed in detail, and the registers meeting the criteria were analysed to obtain data on register history, recorded variables, population, current activity, and clinical outcomes. If detailed evaluation revealed overlapping or consecutive projects from the same administrator, the register with the most recent data was favoured.

## Results of systematic review

The search generated 532 results. After initial title and abstract review, a total of 32 full texts were retrieved for detailed evaluation. Altogether 15 articles regarding five different registers, databases, quality improvement programs or comprehensive audit programs addressing tonsil surgery were identified. Registers were further evaluated with additional internet searches, and their details are summarized in Table 2.

The National Tonsil Surgery Register in Sweden [5, 16–22] and the Clinical Instrument Surveillance Program (CISP) in Wales [23, 24] were the only currently active registers found to be focusing on tonsil surgery quality registration. Comprehensive audit programs in Austria [25–28], in England and Northern Ireland [29–33] and in Scotland [34, 35] were identified, but they have all been terminated, in 2010, 2004 and 2005, respectively.

All programs were administrated by national otorhinolaryngologic societies or governmental institutions. Great variation was seen in coverage, number of operations included and length of time period for inclusion. All registers or audit programs were rather similar with respect to included indicators, with main variables being patient demographics, indications for surgery, surgical methods and techniques, grade of surgeon, and postoperative complications. All programs registered tonsillectomies and adenotonsillectomies. Tonsillotomies were only included in the Swedish register and in the audit program of Austria. The Austrian register was the only one classifying postoperative haemorrhages in a detailed manner. In the Swedish register, information concerning complications after discharge (within 30 days) and symptom relief at 6 months are reported by the patients, whereas in all other registers all variables were reported by health professionals. Different length of follow-up was noted, with 6 months in the Swedish register, 28 days in the UK programs and with a minimum of 1 month in Austria.

## Nordic tonsil surgery register collaboration

Denmark, Finland, Norway and Sweden have a total population of over 26 million people. About 35,000 tonsillectomies or tonsillotomies are performed annually in public and private health care.

The aim of the NTSRC is to provide information to patients and health care professionals on the process and outcome measurements in benign tonsil surgery, to stimulate the improvement of the quality and safety of tonsil surgery, and to obtain evidence-based knowledge for implementing standards for best clinical practice in tonsil surgery. The framework of the NTSRC was adopted from the National Tonsil Surgery Register in Sweden.

### Register database in each country

#### Sweden

Sweden is the biggest Scandinavian country with a population of over 10 million and about 13,500 annually performed tonsil operations. The Swedish National Tonsil Surgery Register has been operational since 1997 under the supervision of the Swedish Association for Otorhinolaryngology Head and Neck Surgery (SFOHH). The register receives financial

**Table 2** Tonsil surgery registries, databases and quality improvement programs identified in systematic review

| Registry | Established | Country | Data elements | Follow-up | Administrator | Description | Status |
|---|---|---|---|---|---|---|---|
| The National Tonsil Surgery Register in Sweden [5, 16–22] | 1997 | Sweden | Patient demographics, operation details, 30 day patient-reported outcome of haemorrhage, pain and infections, 6 months patient-reported outcome of symptom relief | 6 months | National Quality Register of Sweden | Covers over 80% of yearly tonsil operations (tonsillectomies and tonsillotomies) in Sweden. Internet-based information retrieval. Data collection is performed in three stages: surgeon fills patient characteristics and operational details at the time of discharge and patients receive a web-link via email to respond the survey at 30 days and at 6 months. Registry was updated in 2009, and between 2009 and June 2017, over 84,000 operations have been recorded | Active |
| Clinical instrument Surveillance Program (CISP) [23, 24] | 2003 | Wales | Patient demographics, operation details (grade of surgeon, indication, technique of operation and haemostasis, instrumentation details). Details of complications (haemorrhage, pain, vomiting, fever, other) during the index admission or re-admission | 28 days | Public Health Wales | Monitored all tonsillectomy and adenoidectomy surgery performed by NHS hospital in Wales (and associated private hospitals) with the specified single-use instruments in 2003–2015. After a return to reusable instruments in 2015 monitoring is continued to detect whether there is a change in haemorrhagia rates following the transition. Two data collection forms, operation form and postoperative event form. Between 2003 and 2015, over 44,000 operations have been recorded. In 2015, 1999 tonsil operations were recorded and the compliance of returning operation form was 75% compared to only 10% returning the postoperative event form | Active |

**Table 2** (continued)

| Registry | Established | Country | Data elements | Follow-up | Administrator | Description | Status |
|---|---|---|---|---|---|---|---|
| National Prospective Tonsillectomy Audit of England an Northern Ireland [29–33] | 2003 | England and Northern Ireland | Patient demographics, operation details (grade of surgeon, technique of operation and haemostasis, instrumentation details, surgical time). Details of complications (haemorrhage, pain, vomiting, fever, other) during the index admission or re-admission | 28 days | Comparative Audit Group of British Association of ORL-HN surgeons | A comprehensive national audit on tonsillectomies performed in England and Northern Ireland from July 2003 until September 2004. Data from 145 NHS hospitals and 132 independent hospitals on a total of 40,514 patients. Two sheets for data collection: operation sheet and postoperative complication sheet | Inactive |
| A Scottish prospective audit of Tonsil and Adenoid Surgery with Disposable Surgical Instruments [34, 35] | 2002 | Scotland | Patient demographics, operation details (grade of surgeon, technique of operation and haemostasis, instrumentation details, surgical time). Details of complications (haemorrhage, pain, vomiting, fever, other) during the index admission or re-admission | 28 days | Scottish Otolaryngology Society Audit Committee | A prospective audit from March 2002 to March 2005. All patients undergoing tonsillectomy or adenotonsillectomy in private or NHS hospitals in Scotland were included, altogether 14,530 patients. Three sets of data were collected: operative sheet including patient charasteristics and operation details, complications during initial stay, and details of re-admitted patients | Inactive |
| Autrian Tonsil Study [25–28] | 2009 | Austria | About 100 variables collected. Patient characteristics, surgery type, indication, grade of surgeon, operation technique, and postoperative haemorrhage with precise classification | Minimum 1 month | Austrian Society of ORL-HNS and Austrian Society of Pediatrics | October 1st, 2009–June 30th, 2010, a full survey was performed on all tonsillectomies and tonsillotomies with or without adenoidectomy, and solely adenoidectomies, in Austria. A total of 9405 patients were included | Inactive |

support from the Swedish Association of Local Authorities and Regions (SKL). Today, the register includes over 120,000 patients. In Sweden, no active consent is required to include patients in national quality registers, but patients must be informed and they may choose to opt out. The coverage of the tonsil surgery quality register for the last 4 years has been around 80%. Data from the register have been analysed and presented in several publications [5, 16–22].

#### Norway

Norway has 5 million inhabitants and approximately 10,000 tonsil surgery procedures are performed every year. In 2014, the Norwegian ENT department managers made a decision in cooperation with the national ENT society to launch the Norwegian National Tonsil Surgery Register. In September 2016, the Ministry of Health and Care Services in Norway accepted the Tonsil Surgery Register as a national register. The Norwegian National Tonsil Surgery Register has adapted and translated the Swedish dataset. All Norwegian participants must sign a written informed consent before inclusion in the register. The Central Health Region of Norway IT (HEMIT) is responsible for the data solutions within the register. St Olav University Hospital in Trondheim started inclusion of patients as a pilot in January 2017. The nationwide launch started in March 2017, and by January 2018, all 24 hospitals and nine out of 19 private institutions performing tonsil surgery in Norway are recording patients.

#### Denmark

In 2015, a research group was established in Central Region Denmark (1.2 million inhabitants covering about quarter of the total population in Denmark) with the purpose of introducing the tonsil surgery register first in this region and later in all health regions in Denmark. The Swedish National Tonsil Surgery Register IT platform has been translated into Danish and copied to a regional certified server. The Central Health Region of Denmark and the Swedish National Tonsil Surgery Register have ratified an official collaboration agreement, and Danish Data Protection Agency has provided its approval for a register. A pilot register came into operation in Central Region Denmark in September 2017, and the plan is nationwide coverage by the end of 2018.

#### Finland

The Finnish Tonsil Surgery Register launch will take place at the Helsinki University Hospital (HUH), Department of Otolaryngology—Head and Neck Surgery, with a health care district of approximately 1.6 million inhabitants covering about 30% of the population in Finland. HUH hospital district is currently undergoing a total renewal of patient record systems both in the health care sector and within social services. A new integrated system Apotti (Epic Solutions Ltd., Cork, Ireland) will be launched stepwise between 2018 and 2020. One major advantage in Apotti is structured patient record system, which enables automatic data retrieval for quality registration purposes. Thus, the Finnish approach differs from the other Nordic Tonsil Surgery Register databases in terms of retrieving data automatically from electronic patient records, and no separate consent from patients is required. The structured patient records in tonsil surgery are designed to include all the elements of NTSRC, and the Finnish Tonsil Surgery Register is expected to be operational in 2019. After piloting the register system at the Helsinki University Hospital, the ambition is to expand the system nationwide in the future.

### Variables

Data collection of the NTSRC is carried out in three stages. The surgeon completes patient demographics and operation-related information at the time of surgery. These variables are presented and defined in Table 3. Postoperatively, the patients receive e-mails, SMSs, or messages in their digital mailbox (Norway) 30 days and 6 months postoperatively with a web-link to the questionnaires, covering patient-reported postoperative recovery and complications. Table 4 summarizes data obtained from the patient questionnaires.

### Data management

Each participating health care unit has a data administrator, who will hold access to local data. In addition, each country has appointed at least one national data controller, who has access to the national data. Sweden administers the common database, and data transferring from national databases will be carried out two to four times per year.

Each national register collects the personal identification information, but it is removed before merging the data into the common Nordic register. The resulting anonymous data are treated with confidentiality, fulfilling the requirements of the data protection agencies in the individual countries. Mutual reports enabling comparison of outcome from all participating clinics will be created annually.

### Other aspects of the collaboration

Regular meetings of the NTSRC steering committee form the basis of co-operation. Meetings enable close partnership in developing the national registers, establishing equal standards, sharing the best practices and envisioning of common research projects. The chairmanship will alternate between participating countries in 2-year cycles. NTSRC has received funding from NordForsk, an

**Table 3** Variables completed by surgeon in Nordic Tonsil Surgery Register

| Variable | Definition |
|---|---|
| Date of birth | |
| Date of surgery | |
| Patients e-mail address | |
| Indication of surgery | |
| Airway obstruction/snoring/hypertrophic tonsils | Tonsils cause breathing disorder during sleep (parent reported) |
| Recurrent tonsillitis | At least three episodes of acute tonsillitis during last 12 months |
| Peritonsillar abscess | Peritonsillar abscess or peritonsillitis warranting emergency operation, or history of peritonsillar abscesses/peritonsillitis |
| Chronic tonsillitis | Prolonged inflammation of the tonsils (at least 3 months) affecting daily activities |
| Systemic complication of tonsillitis | Systemic disease that is aggravated by tonsillitis, for example, psoriasis |
| Other | Free text field to record other indications |
| Surgical unit | |
| Day-case surgery | No admission for overnight |
| Day-case surgery converted to admission | Surgery planned day-case basis, but overnight admission required |
| Overnight surgery | Prearranged overnight admission |
| Overnight surgery with extended admission | Prearranged overnight surgery extended to multiple nights |
| Type of surgery | |
| Primary surgery | No previous tonsil surgery performed |
| Revision surgery | Tonsillectomy or tonsillotomy performed previously |
| Extent of surgery | |
| Tonsillectomy only | Extracapsular removal of tonsils |
| Tonsillectomy and adenoidectomy | Extracapsular removal of tonsils and removal of adenoid |
| Tonsillotomy only | Partial removal of tonsils |
| Tonsillotomy and adenoidectomy | Partial removal of tonsils and removal of adenoid |
| Surgical technique | |
| Cold steel | Procedure performed with cold instruments only, for example, knife, scissors or elevator |
| Radiofrequency | Radiofrequency energy is used for cutting and coagulation |
| Diathermy scissors | Procedure performed with bipolar diathermy scissors, which can simultaneously cut and coagulate |
| Ultracision | Procedure performed with instrument, which simultaneously cuts and coagulates using ultrasonic vibration |
| Dissection with bipolar diathermy | Tonsils are dissected using bipolar diathermy |
| Other | Free text field to record other techniques |
| Technique for haemostasis | |
| Infiltration with local anaesthetic and adrenalin | Haemostasis achieved with adrenaline vasopressor effect |
| Monopolar diathermy | Heat coagulation of the vessels using monopolar diathermy |
| Bipolar diathermy | Heat coagulation of the vessels using bipolar diathermy |
| Ligature | Ligation used for haemostasis |
| Suture ligature | Suture with needle used for haemostasis |
| Radiofrequency | Haemostasis achieved using radiofrequency instruments |
| None | Haemostasis achieved with compression only |
| Other | Free text field to record other techniques |
| Primary haemorrhage requiring intervention (Yes/No) | Any haemorrhage requiring intervention and occurring after extubation during initial hospital stay |

organization providing support for Nordic cooperation on research, managed by Nordic Council of Ministers.

The National Tonsil Surgery Register in Sweden has developed innovative information services to utilize and learn from the register data. The register has webpages for both patients and professionals. Professional webpages offer versatile statistical data to allow comparison of different health care units and their outcomes [36]. Swedish

**Table 4** Nordic Tonsil Surgery Register data acquired from patient questionnaires

| Questionnaire at 30 days |
|---|
| Bleeding requiring a contact to health services (Y/N) |
| Bleeding requiring hospital re-admission (Y/N) |
| Surgery performed to stop the bleeding (Y/N) |
| Infection within 30 days of the operation (Y/N) |
| Infection requiring a contact to health services (Y/N) |
| Infection requiring antibiotic treatment (Y/N) |
| Pain requiring a contact to health services (Y/N) |
| Days until pain free |
| Days until returning to normal diet |
| **Questionnaire at 6 months** |
| Symptom relief after 6 months |
| Symptoms are gone |
| Symptoms are almost gone |
| Symptoms remain |
| Symptoms have increased |

platforms are available also for NTSRC data management and they provide a valuable tool to comprehensively exploit register data. Swedish patient education webpages aim to provide accurate information for patients and their families on tonsil surgery, postoperative care, complications, and pain management (http://www.tonsilloperation.se). As a part of the Nordic cooperation, patient education webpages have been translated into all Nordic languages to serve also Danish, Finnish and Norwegian patients. Arabic, English, and Spanish translations also exist. The Norwegian National Tonsil Surgery Register has also opened their national webpages, where results from the Norway will be subsequently presented.

## Discussion

Although tonsillectomies and tonsillotomies are common operations with history stretching back centuries, there is considerable variation in applied clinical practices within and between different countries. There is an evident need for general guidelines and constant quality improvement actions, and surgical quality registers can serve as platforms for enhancing the safety and the outcome of surgery. The present study evaluated the existing tonsil surgery registers available in literature and presents the project to establish the Nordic Tonsil Surgery Register Collaboration.

We systematically reviewed the literature and identified five prospective registers, quality assurance programs or comprehensive audit programs with the inclusion principle of tonsil surgery. The National Tonsil Surgery Register in Sweden and the Clinical Instrument Surveillance Program in Wales have ongoing activity. National audit programs in Austria, England and Northern Ireland, and Scotland were all limited in duration.

National register efforts for tonsil surgery have served especially in monitoring safety issues. The Austrian audit program was initiated after five cases of fatal post-tonsillectomy haemorrhage in children between 2006 and 2007. These tragic incidents raised the need to evaluate validity of indications and surgical techniques in different age groups [25]. The audits of Scotland, England and Northern Ireland, as well as CISP in Wales, were all started in response to concerns about the safety of tonsil surgery following the introduction of single-use surgical instruments, after a theoretical risk of transmission of Creutzfeldt–Jakob disease (vCJD) from reusable surgical instruments was identified [37]. Recently, the transmission risk of vCJD in tonsil surgery has been refuted, and the use of disposable instruments is no longer warranted [24]. During the transition to reusable instruments, CISP carries on the tonsil surgery surveillance to ensure a safe changeover [38]. Another incentive for audits in United Kingdom was a year by year increase in post-tonsillectomy haemorrhage rates, suspected to be related to growing popularity of diathermy technique [30].

In addition to the five registers identified in the present systematic review, pursuits for establishment of tonsil surgery quality register systems exists, Australia being a good example. Web-based tonsil surgery register database according to the Swedish formula is under construction there, and expected clinical launching is in 2018 (personal communication with Anders Cervin 2017).

International register collaboration provides more extensive datasets to study infrequent events and allows comparisons between participating countries to critically evaluate the national clinical traditions. Several international register co-operations in the other fields of surgery exist [39–46], but international register collaboration in Otorhinolaryngology—Head and Neck Surgery has not, to our knowledge, been previously reported. NTSRC was established in 2016 with the objective to launch national tonsil surgery quality registers with uniform indicators, and thereby provide valuable benchmarks for evaluation of the quality of care, and in the end improve the outcome of tonsil surgery in the Nordic countries.

The quality of the register data is strongly dependent on the consistency of definitions [47]. The strength of the NTSRC is that consistency of definitions can be ensured from the very beginning, as Danish, Norwegian, and Finnish registers were only at the development stage at the time of launching the co-operation. By establishing national registers with uniformly defined variables and congruent methods of data collection, we may aggregate data, perform relevant analyses and obtain reliable outcome information on tonsil surgery in the Nordic countries.

In 2006, Michael Porter and Elizabeth Teisberg launched the concept of value-based health care [48]. The guiding principle is to set value as a goal, and measure it by dividing outcome that matter to patients with costs of delivering this outcome. For value evaluation, defining feasible outcome measurements that matter the most to the patient is essential. Since 2012, the International Consortium for Health Outcomes Measurement (ICHOM) has responded to the challenge of implementing value-based health care by developing standard sets of outcomes and related risk factor measures for over 20 specific medical conditions [49]. However, standards for tonsil surgery have not yet been created. In the NTSRC, outcome measures are built on 20-years of experience from the National Tonsil Surgery Register of Sweden. Measures' validity has been tested, and their feasibility has been demonstrated in the form of successful quality improvement initiatives [20, 50]. As populations and health care systems in the other Nordic countries are very similar, the Swedish experience should be considered valid and can be applied accordingly in the other national registers of the NTSRC. The Swedish and Norwegian registers are nationwide, covering both the public and private sector, and therefore reflect the clinical practice in the entire country. In both Denmark and Finland, the registration is initiated regionally in one health care district and only in the public sector. Consequently, this might influence the external validity of these registers. However, in the future, both Denmark and Finland have intentions to expand their registers to cover the whole country.

The main challenge with quality registering is to achieve representable results through high coverage and accuracy of register data, along with high positive predictive values (PPV) of the indicators included in the register. In the Swedish national tonsil surgery register, the coverage of data supplied by health care professionals has recently been over 80%, but response rate for 1 and 6-month outcome surveys remains slightly above 40% [51]. PPV have been tested to be 85–95% for the Swedish National Patient Register (NPR), covering all inpatient and specialized outpatient care in Sweden, but no comprehensive external validation has been made of tonsil register [52]. However, a match of re-admission data between the NPR and the Swedish Tonsil Surgery Register have shown conformity [17]. It is, in the authors' opinion, likely that the NTSRS numbers are comparable to those reported from the NPR.

In all participating countries, national ENT-specialist societies have been actively developing and supporting the register activities and enhancing physicians' commitment to comprehensive registration. In the Finnish system, the first phase register information is captured with a structured patient record system, ensuring high coverage. In other NTSRC countries, physicians supply patient characteristics and operation details via a web-based platform. In the future, we aim to develop the registration process towards automated information retrieval also in Sweden, Norway, and Denmark. The challenge of ensuring patient compliance in the registration process remains, and will be addressed by raising patients' awareness of the benefits of the registration and presenting the results openly on easy-access webpages.

In surgery, observational studies often better reflect reality and provide more complete overview of outcome and complications compared to randomized controlled trials (RCT). Observational studies, like registers, are used to create hypotheses, which can be tested with RCT's. Ironically, the recent trend in tonsil surgery research seems to have been the other way around. The NTSRC will take the process one step further, and could hopefully result in new RCT's answering the questions we will need to ask to improve the quality and safety of tonsil surgery.

## Conclusions

With millions of tonsillectomies and tonsillotomies performed worldwide every year it is surprising that only two active tonsil surgery quality registers could be identified in a systematic literature review. Great diversity in current clinical practise of tonsil surgery exists and with being among the most frequently performed surgical procedures worldwide there is a need for evidence-based guidelines. The Swedish National Tonsil Register has been used as a model for introducing similar registers in Denmark, Finland and Norway, resulting in the presented NTSRC. International register collaboration enables comparison between countries and a larger data pool for surveillance, quality assurance and research. NTSRC has great potential in establishing unambiguous guidelines and improving the current clinical practise of tonsil surgery.

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## Compliance with ethical standards

**Conflict of interest** The authors declare that they have no conflict of interest.

**Ethical approval** This article does not contain any studies with human participants or animals performed by any of the authors.

**Disclaimer** Data from the Norwegian Patient Register has been used in this publication. The interpretation and reporting of these data are the sole responsibility of the authors, and no endorsement by the Norwegian patient register is intended nor should be inferred.

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