The Swedish National Airway Register (SNAR): development, design and utility to date

C Stridsman, J R Konradsen, L Vanfleteren, C Pedroletti, J Binnmyr, P Edfelt, K Fjällman Schärberg, Y Sjöö, F Nyberg, A Lindberg, A Tunsäter and A Ekberg-Jansson

*Department of Public Health and Clinical Medicine, Division of Medicine, the OLIN-unit, Umeå University, Umeå, Sweden; ‡Department of Women’s and Children’s Health, Karolinska Institutet, Stockholm, Sweden; §COPD Center, Department of Respiratory Medicine and Allergology, Sahlgrenska University Hospital, Gothenburg, Sweden; ¶Department of Internal Medicine and Clinical Nutrition, Institute of Medicine, Sahlgrenska Academy, Gothenburg University, Gothenburg, Sweden; €Department of Woman and Child Health, Uppsala University, Uppsala, Sweden; ØStädtälje General Hospital, Sweden; †The Swedish Asthma- and Allergy Association, Stockholm, Sweden; ‡The Swedish Asthma- and Allergy Research Foundation, Stockholm, Sweden; ‡The Swedish Heart and Lung Association, Stockholm, Sweden; ‡The Swedish National Airway Register, Gothenburg, Sweden; ‡School of Public Health and Community, Institute of Medicine, Sahlgrenska Academy, Gothenburg University, Gothenburg, Sweden; Department of Respiratory Medicine and Allergology, Skåne University Hospital, Lund University, Lund, Sweden

**ABSTRACT**

**Background:** The Swedish National Airway Register (SNAR) was initiated in 2013 to ensure and improve the quality of care for patients with asthma and COPD.

**Aim:** To describe the development and design of SNAR, and to study the 2019 data to evaluate its potential utility related to improvement of quality of care.

**Methods:** SNAR includes data from patients with asthma (both children and adults) and COPD from primary, secondary and tertiary care, and also, for COPD inpatient care. Data on diagnostic investigations (e.g. spirometry, blood sample, skin prick test), symptom-scores, comorbidities and prescribed treatments are registered. The registrations are entered manually by healthcare professionals, or directly transferred from electronic medical records to a web-based platform.

**Results:** In 2019, 1000 clinics participated and data were directly transferred by about 88% of them. The register included data on 205,833 patients with asthma and 80,372 with COPD (of these, 5% had both diagnoses). Registrations of new patients and follow-up visits from primary and secondary/tertiary care in 2019 were completed for 75,707 patients with asthma (11,818 children <12 yr, 6545 adolescents 12–17 yr, and 57,344 adults >17 yr) and 38,117 with COPD. Depending on age and disease group, 43–77% had performed spirometry, 36–65% Asthma Control Test, and 60% COPD Assessment Test. The prevalence of current smoking was about 2% in adolescents, 10% in adults with asthma, and 34% in COPD. For these, smoking cessation support was offered to 27%, 38% and 51%, respectively. Overall, limited data were available on investigation of allergy, 6-min walk test, patient education and written treatment plans. Regarding asthma, sex-differences in disease management were evident.

**Conclusion:** SNAR has cumulatively registered data from over 270,000 individuals, and the register is important for patients, caregivers, authorities, politicians and researchers to evaluate the effect of treatment and to ensure high and equal quality of care nationwide.

**Introduction**

**The Swedish National Airway Register**

The global prevalence of asthma and chronic obstructive pulmonary disease (COPD) varies between countries [1–3]. In Sweden, the prevalence of asthma is estimated to be 7% in children aged 7–8 years [4], and about 10% in adolescents and adults [2,5]. Approximately 0.5% of the general population suffers from severe asthma [6,7]. In parallel with the decrease in smoking rates in Sweden [8], the prevalence of COPD has decreased and is nowadays around 8% [9,10]. Nevertheless, both asthma and COPD are associated with a high burden of symptoms, recurrent exacerbations and extensive health-care utilizations [11,12]. The main cost driver in COPD are hospitalizations due to comorbidities [13,14], and costs for hospitalization, medications and work/school absenteeism are substantial in asthma [15,16].

An important task for a national quality register is to provide a longitudinal and nationwide survey of the...
care of patients with obstructive lung diseases in order to identify inequalities, sub-optimal care and knowledge gaps. The Swedish National Airway Register (SNAR) [17] was initiated in 2013 as a result of merging two existing registers: the National COPD Register (RiksKOL, initiated 2009) and the National Asthma Register (NAR, initiated 2009). The quality register is comprehensive, including data from patients with asthma (both children, adolescents and adults) and COPD from primary, secondary and tertiary care as well as hospitalized COPD patients. In 2015, the Swedish National Board of Health and Welfare published new national guidelines for care and treatment of patients with asthma and COPD [18]. At that time, the variables in SNAR were modified to harmonize with these recommendations, which presents a unique opportunity to use data from SNAR to evaluate the effect of this national effort. Several papers presenting COPD data from SNAR have been published [19–22]; however, a comprehensive presentation of SNAR across the spectrum of obstructive lung disease has not yet been undertaken. Accordingly, this paper aims to describe the development and design of SNAR, and to study the 2019 data to evaluate its potential utility related to improvement of quality of care.

**Methods**

**Registrations**

Following a physician diagnosis of asthma and/or COPD and obtaining informed consent, the registrations are directly transferred from electronic medical records (EMR) or entered manually by health-care professionals to a web-based platform supported by the Centre of Registers Västra Götaland, Sweden [23].

The registrations include data about the current level of health care (primary, secondary, tertiary or inpatient care), symptom-scores, comorbidities, diagnostic investigations (e.g. spirometry, blood sample, skin prick test) and prescribed treatment (both pharmacological and non-pharmacological) (Table 1). In Sweden, spirometry is predominantly performed according to the ERS/ATS guidelines [24], and both pre- and post-bronchodilator values can be registered in SNAR. Allergic sensitization can be diagnosed either by skin prick test or by analysing allergen-specific IgE antibodies to airborne or food allergens. Current smoking is defined as daily smoking or smoking cessation during the last 6 months. Smoking cessation support is registered when nicotine replacement therapy or motivational interviewing is offered to current smokers. The history of exacerbations in the year previous to registration is documented. For patients with asthma, the Asthma Control Test (ACT) is used to detect the level of asthma control, and an ACT score ≤19 is defined as uncontrolled asthma [25–27]. The COPD Assessment Test (CAT) measures the health status impairment in COPD [28], and a CAT score ≥10 indicates an impairment of importance [11]. A CAT score ≥18 is a suggested redefinition of a high symptom burden [29]. Further, regarding COPD, severity of airflow limitation is based on FEV1/% predicted and divided into the Global Initiative for Chronic Obstructive Lung Disease (GOLD) stage 1–4 (mild to very severe COPD), and

**Table 1. An overview of data and variables in the Swedish National Airway Register (SNAR).**

| Organization and equipment | Characteristics | Comorbidities | Health status and symptoms |
|---------------------------|----------------|---------------|---------------------------|
| **Type of care** | COPD diagnosis | Anxiety/depression | Asthma Control Test (ACT) |**
| **Visit date** | Asthma diagnosis | Diabetes mellitus | mMRC dyspnea scale |**
| **Resources per week (nurse hours/week)** | Allergy diagnosis | Heart disease | Interprofessional care |
| **University credits (nurse)** | Smoking habits/Pack year | Hypertension | Physiotherapist |
| **Medical responsibility (physician)** | Passive smoking | Osteoporosis | Dietician |
| **Access to interprofessional collaboration** | Spirometry | Sleep apnoea syndrome | Occupational therapist |
| **Access to smoking cessation support** | Saturation | Alpha-1-Antitrypsin deficiency | Psychologist |
| **Spirometer** | Action if saturation <93% | Lung neoplasms | Physical capacity |
| **Oximeter** | FeNO | Nasal polyps | Physical activity (days/week) |
| **Nebulizer** | Provocations | Eczema | 6-minute walk test |**
| **FE NO** | Investigation of allergy | Rhinitis | Patient education |
| **Oxygen equipment** | Blood sample (e.g. eos, IgE) | COVID-19 | Smoking cessation support |
| **Sex** | Skin prick test | Pharmacological treatment | Structured patient education |
| **Age** | Triggers | For COPD | Individual |
| **Height** | Disease severity | For asthma | In group |
| **Weight** | Number of exacerbations | For allergy | Written treatment plan |
| **Body Mass Index (BMI)** | Number of hospitalizations | Antibiotics and/or OCȘ | |
| **Action if low BMI (<22)** | Date of death | Influenza vaccination | |

*Primary, secondary, tertiary or inpatient care (inpatient care only for COPD) \( ^2 \)Registered only for patients with COPD \( ^3 \)Registered only for patients with asthma \( ^4 \)Skin prick test and/or allergen-specific IgE antibodies \( ^5 \)Last 12 months \( ^6 \)Last five years.

Abbreviations: FeNO = fractional nitric oxide (NO) concentration in exhaled breath. OCȘ = Oral corticosteroids. Provocations = Exercise challenge tests, Dry air, Mannitol, Metacholine or Histamine. Eos = eosinophils. IgE = Immunoglobulin E.
further classified into categories A, B, C or D based on CAT score and exacerbation history according to the GOLD document [11]. The 6-min walk test is a self-paced test of walking capacity in COPD [30]. Patient education is a structured education designed to improve patient knowledge of the diseases, treatment, inhalation technique, self-care and risk factors. The goal of a written treatment plan (asthma action plan/management plan) is to strengthen self-care, reduce/prevent exacerbations and emergency department visits [11,12].

The current study based on SNAR was approved by the Swedish Ethical Review Authority (2019–04915) and includes data recorded in SNAR from 2014 to 2019. Due to technical difficulties during implementation registrations in 2013 were excluded. Mortality data were collected from The National Cause of Death Register at The Swedish National Board of Health and Welfare.

**Statistical analyses**

SAS software (SAS Institute Inc, Cary, NC, USA) was used for data management and statistical analyses. Data extraction was conducted 3 February 2020 and included 1) new registrations of patients 2014–2019, 2) cumulative number of registered patients 2014–2019, and 3) registrations of variables for each unique patient from the last 15 months before their last visit in 2019. Analyses were based on manually entered and directly transferred data from primary and secondary/tertiary care. In directly transferred data, missing data on a particular variable was interpreted as negative/not performed. For comparison between groups Fishers’s Exact test (lowest 1-sided p-value multiplied by 2) was used for dichotomous variables. A p-value <0.05 was considered statistically significant.

**Results**

**Numbers of registered patients**

Table 2 demonstrates new registrations and cumulative numbers of registered patients, as well as deceased patients in the years 2014–2019. Since 2014, 15,225–43,006 new patients with asthma, and 7456–16,843 with COPD have been registered annually. In 2019, 205,833 patients with asthma were included in the register, and 80,372 with COPD, respectively (Table 2). Of these, 14,324 had both an asthma and COPD diagnosis (Asthma COPD Overlap Syndrome, ACOS); and henceforth in this paper, these individuals are analysed as COPD patients.

**Registrations in 2019**

In 2019, clinic participation in SNAR varied, with some counties having only one participating clinic whilst in other counties all clinics participated. Counties with the highest number of registrations were Stockholm, Västra Götaland, Skåne, Värmland and Gävleborg. In total, 853 primary care clinics, 125 secondary/tertiary care clinics (whereof 62 were paediatric clinics) and 22 inpatient wards were included. Data had been manually entered for 12% and directly transferred from EMRs for 88% of the clinics.

A total of 75,707 patients with asthma had one or more registrations of a new patient visit and/or follow-up visit in 2019. Of these, 15.6% were children <12 years (mean age 6.5 years, 38.4% girls), 8.6% were adolescents 12–17 years (mean age 14.9 years, 45.8% girls) and 75.7% were adults >17 years (mean age 53.9 years, 62.5% women). Regarding COPD, 38,117 patients had registrations (mean age 73.0 years, 57.3% women) distributed by GOLD 1–4; 14.6% GOLD 1, 56.3% GOLD 2, 24.2% GOLD 3 and 5.0% GOLD 4. Additionally, by GOLD A-D; 27.2% GOLD A, 59.5% GOLD B, 1.9% GOLD C and 11.0% GOLD D.

**Children with asthma (<12 yr)**

Spirometry data were available from 42.6% of the children, and 14.8% had undergone investigation of allergy. Data on ACT were available for 35.8%, and of these, uncontrolled asthma was reported by 24.0%. Patient education and written treatment plans were reported for 29.3% and 17.5%, respectively. A higher proportion of boys than girls had undergone investigation of allergy, and had received a written treatment plan, while more girls had uncontrolled asthma (Table 3).

**Adolescents with asthma (12-17 yr)**

Among adolescents with asthma, spirometry data were reported for 77.3%, and 27.2% had undergone investigation of allergy. The proportion of current smokers was 1.9%, whereof 26.6% had been offered smoking cessation support. Data on ACT were available from 65.1%, and among them, 30.0% had uncontrolled asthma. A higher proportion of girls than boys were current smokers and had uncontrolled asthma, while more boys had undergone spirometry, received patient education and a written treatment plan (Table 3).

**Adults with asthma (>17 yr)**

Data on spirometry and investigation of allergy were available from 57.9% and 15.3% adults with asthma, respectively. The prevalence of current smoking was
Table 2. New registrations and cumulative number of patients in the Swedish National Airway Register (SNAR) 2014–2019, stratified by asthma and COPD, respectively.

| Year | 2014 | 2015 | 2016 | 2017 | 2018 | 2019 |
|------|------|------|------|------|------|------|
| New registrations of patients with asthma* | | | | | | |
| Manually or directly transferred data, n | 15,225 | 23,673 | 38,161 | 43,006 | 41,411 | 34,777 |
| Cumulative number of patients with asthma* | | | | | | |
| Manually entered data n | 6126 | 14,679 | 24,855 | 35,638 | 44,218 | 52,870 |
| Directly transferred data, n | 18,813 | 34,429 | 63,368 | 96,918 | 131,359 | 158,837 |
| Manually or directly transferred data, n | 24,804 | 48,478 | 86,639 | 129,645 | 171,056 | 205,833 |
| Deceased, n | 75 | 256 | 640 | 1409 | 2567 | 4073 |

*Irrespective of concomitant COPD diagnosis

| Year | 2014 | 2015 | 2016 | 2017 | 2018 | 2019 |
|------|------|------|------|------|------|------|
| New registrations of patients with COPD* | | | | | | |
| Manually or directly transferred data, n | 7456 | 10,224 | 16,247 | 16,843 | 13,988 | 10,160 |
| Cumulative number of patients with COPD* | | | | | | |
| Manually entered data, n | 6391 | 10,919 | 16,154 | 21,545 | 25,603 | 28,924 |
| Directly transferred data, n | 6752 | 12,882 | 24,716 | 37,371 | 48,589 | 56,216 |
| Manually or directly transferred data, n | 12,910 | 23,134 | 39,381 | 56,224 | 70,212 | 80,372 |
| Deceased, n | 355 | 1037 | 2272 | 4543 | 7676 | 11,467 |

*Irrespective of concomitant asthma diagnosis.

9.6%, and 37.6% of these had been offered smoking cessation support. ACT had been used in 44.2% of the patients, and of these 38.2% had uncontrolled asthma. Of the adults, 32.8% had undergone patient education and 6.3% received a written treatment plan. A higher proportion of women than men were current smokers and had an uncontrolled asthma, while a higher proportion of men had undergone spirometry, patient education and received a written treatment plan (Table 3).

Chronic obstructive pulmonary disease

Among patients with COPD, spirometry data were available for 71.5% of the patients, and a 6-min walk test for 5.2%. Further, 33.5% were current smokers, of whom 51.0% had been offered smoking cessation support. CAT was recorded in 59.8% of the patients; of these 70.7% had a CAT score ≥10, and 25.7% had a score >18. Patient education and written treatment plan were reported for 46.2% and 9.5%, respectively.

The prevalence of current smoking was higher among women than men, while other disease management characteristics were quite similar between men and women (Table 4).

Discussion

Sweden has a long history of using national quality registers with the aim of supporting improvement of care and treatment [23,31–34]. To date, SNAR is implemented in all counties in Sweden and in total over 270,000 patients with asthma and COPD have been registered. The register provides a unique insight into the entire Swedish healthcare system: primary care, paediatrics, internal medicine, pulmonology and allergology in adults and children in both general and university hospitals. Regarding COPD, the register also includes data on inpatient care. Our result revealed an insufficient adherence to the national guidelines for the

Table 3. Children, adolescents and adults with asthma only with registrations in the Swedish National Airway Registrar (SNAR) in 2019 including both new patient registrations and follow-up visits for existing registry patients in primary and secondary/tertiary care.

|                          | Children (<12 yr) with asthma | Adolescents (12–17 yr) with asthma | Adults (>17 yr) with Asthma |
|--------------------------|-------------------------------|-----------------------------------|----------------------------|
|                          | Girls n = 4543 Boys n = 7275 | Boys n = 2998 Girls n = 3547 Boys n = 35,842 Men n = 21,502 |
| Spirometry, n (%)        | 1913 (42.1) 3123 (42.9)      | 2265 (75.6) 2797 (78.9)          | 20,316 (56.7) 12,896 (60.0) |
| Investigation of allergy, n (%) | 613 (13.5) 1131 (15.5) | 788 (26.3) 994 (28.0)         | 5471 (15.3) 3300 (15.3) |
| Current smoking (%)      | 53 (2.8) 26 (1.1)           | 53 (2.8) 26 (1.1)              | 2718 (10.0) 1491 (8.9) |
| Offered smoking cessation, n (%) | 17 (32.1) 4 (15.4) | 17 (32.1) 4 (15.4)           | 1040 (38.3) 542 (36.4) |
| Asthma Control Test (ACT), n (%) | 1571 (34.6) 2656 (36.5) | 1863 (62.1) 2396 (67.6) | 15,506 (43.3) 9846 (45.8) |
| ACT ≤19, n (%)           | 424 (27.0) 602 (22.7)       | 744 (39.9) 534 (22.3)         | 6374 (41.1) 3307 (33.6) |
| Patient education, n (%) | 1307 (28.8) 2156 (29.6)     | 1453 (48.5) 1909 (53.8)       | 11,510 (32.1) 7273 (33.8) |
| Written treatment plan, n (%) | 746 (16.4) 1328 (18.3) | 634 (21.1) 924 (26.1)       | 2181 (6.1) 1432 (6.7) |

*Percentages calculated for those with complete data on smoking habits.

#Percentages calculated for current smokers and patients with data on ACT, respectively.
P-values for differences between groups. Bold values indicating p-values <0.05.
Table 4. Patients with COPD (including ACOS) with registrations in the Swedish National Airway Register (SNAR) in 2019 including both new patient registrations and follow-up visits for existing registry patients in primary and secondary/tertiary care.

|                      | Women                  | Men                     | p-value |
|----------------------|------------------------|-------------------------|---------|
| Spirometry, n (%)    | 15,540 (71.2)          | 11,704 (71.9)           | 0.150   |
| Current smoking (%)a | 6310 (34.7)            | 4450 (31.9)             | 0.001   |
| Offered smoking cessation, n (%) | 3172 (50.3) | 2317 (52.1) | 0.069   |
| COPD Assessment Test (CAT), n (%) | 13,065 (59.8) | 9717 (59.7) | 0.730   |
| CAT >10, n (%)b      | 9184 (70.3)            | 6925 (71.3)             | 0.110   |
| CAT >18, n (%)b      | 3403 (26.0)            | 2441 (25.1)             | 0.120   |
| 6-minute walk test, n (%) | 1184 (5.4)  | 817 (5.0)              | 0.082   |
| Patient education, n (%) | 10,163 (46.6) | 7434 (45.6) | 0.081   |
| Written treatment plan, n (%) | 2108 (9.7)  | 1515 (9.3)             | 0.250   |

*Percentages calculated for those with complete data on smoking habits. 
bPercentages calculated for current smokers and patients with data on CAT, respectively. 
P-values for differences between groups. Bold values indicating p-values <0.05.

Care of patients with asthma or COPD. In particular, investigation of allergy and offered smoking cessation support are areas that need improvement. Furthermore, many patients have not received a written treatment plan and education about their disease as recommended. Regarding asthma, sex-differences in disease management were evident. These findings emphasize the importance of registration in order to further increase the utility of SNAR as a tool to increase quality of care.

A major strength with the register is the implementation of directly transferred data. During the registers first years, data were manually registered by health-care professionals with support of registry coordinators with high skills in obstructive lung diseases. In general, manual entry provides data of high quality but results in fewer registrations. Over time a clear shift in the registration process has been observed towards an increasing proportion of directly transferred data from EMRs to the registry. Today, the majority of the data are directly transferred, which has increased the number of registrations substantially. Direct transfer to the registry is essential for multiple reasons. 1. Data transmission is not time-consuming and does not depend on the goodwill of the health-care provider. 2. It facilitates a higher number of registered individuals, which increases the completeness of the registry. 3. It provides the possibility to build in innovative solutions in the EMR that give direct feedback from the register to health-care providers for quality control.

Although there is an increased coverage related to direct transfer, a limitation is that there are missing reports related to the comprehensiveness of the data and variables in SNAR. Missing reports may be due to absence of data, incorrect data transfer or under-documentation in the EMR. The latter is an important marker for the quality of care and synchronized templates between EMRs and SNAR are of importance and may both improve the representativeness of the data in SNAR and adherence to guidelines in local practice. Register coordinators are continuously working to maintain secure data transfer by supporting health-care units with synchronized templates and validating incoming data. By validating data, the representativeness of each variable can be assessed [23].

As described above, directly transferred data have increased the completeness of the register by increasing the number of participating counties, clinics and registered patients. Further, it has reduced the risk that only clinics with more competence and interest in asthma and COPD registers in SNAR. However, despite the high number of patients in the register, its completeness needs to be considered and discussed. In general, asthma is both under- and over-diagnosed [35] and COPD is still highly under-diagnosed [36], which complicates assessment of completeness. Thus, in the register, both diseases are based on physician-diagnosis and with >200,000 registered patients with asthma, we estimate that SNAR represents about half of all diagnosed patients with asthma on maintenance treatment with inhaled corticosteroids. Further, with >80,000 patients with COPD, it covers of about 85% of diagnosed patients with moderate to very severe COPD. However, due to the under-diagnosis, individuals that have not yet been identified in healthcare are missing from the statistics. In our opinion, SNAR already has a fair completeness for asthma and COPD outpatient health care in Sweden, although the goal is to increase both the total number of patients registered, and also the amount of data registered per patient.

Data from SNAR will provide healthcare professionals, as well as authorities and politicians, with indications of important areas of improvement in respiratory healthcare. Therefore, this paper aimed to present some descriptive clinical data from 2019 and earlier to provide a register overview. Spirometry data from the last 15 months were available on a high proportion of patients, indicating relatively good adherence to guidelines recommendations. Physicians in Sweden report that spirometry is used frequently in primary care [36], but insufficient interpretation skills are a common problem [36,37]. A two-day spirometry training has been implemented in Sweden [38], and we can speculate that the targeted intervention has increased the number of spirometry tests on national level.

The prevalence of current smoking was higher among patients with COPD (34%), and also among those with
asthma (10%), compared to the general population in Sweden (7%) [8]. In the general population, there were no differences by sex. In contrast, data from SNAR showed a higher prevalence of current smoking among women than men, both in asthma and COPD. Importantly, this was also seen among adolescents, with nearly 3% of the girls being current smokers compared to 1% of boys. Furthermore, despite strong recommendations [11,12,18] smoking cessation support was only offered to less than half of the smokers. Smoking cessation is one of the most important therapeutic goals in asthma and COPD patients. It is the only intervention that may stop the progression of COPD [39] and is associated with considerable improvement in lung function and better symptom control in asthma [40]. It is essential to improve the availability of smoking cessation support, not least among younger patients with asthma being a key risk group for developing COPD later in life.

The results indicate that only about half of the patients in Sweden with asthma and COPD were given the opportunity to use the self-administrated questionnaires ACT and CAT, which are highly recommended instruments for use within the clinic [11,12,18]. However, uncontrolled asthma was reported by 25–44% of those tested with ACT, more frequently in girls and women than in boys and men. Further, about 70% of tested patients with COPD, had a CAT score ≥10, and 25% had a high burden of symptoms with a CAT score ≥18. Patients with uncontrolled asthma and high symptom burden in COPD are important to identify. These patients are in need of follow-up visits, and treatment should be adjusted according to guidelines [11,12]. This is clearly an area for further improvement of care.

The proportion of patients with available data on investigation of allergy, the 6-min walk test, patient education, and written treatment plans was limited, indicating either low adherence to current guidelines or incomplete data capture. Nevertheless, other studies have also shown low adherence to, for example, action plans; in one study only about 3% of patients with asthma in the USA had received an action plan [41]. Furthermore, despite limited data, we could observe sex-differences of importance especially among those with asthma; a higher proportion of women than men were current smokers and had uncontrolled asthma, while it seems to be a trend that men receive more efforts in terms of spirometry, investigation of allergy, patient education, and written action plans. Again, this seems to be an area where improvement and more equal access to care is warranted. In order to provide an up-to-date perspective on the care and treatment, statistics and annual reports are visualized on the register website [17].

Future research directions include the possibility to link quality registers with other national registers using the national ID number of each Swedish resident, which makes the large database in SNAR a unique data resource for respiratory research. For example, the Swedish National Board of Health and Welfare maintains health data registers such as the National Causes of Death Register, the Medical Birth Register, the National Patient Register and the Swedish Prescribed Drug Register [42]. Further, data about sociodemographic aspects such as income and educational level can be provided by the Longitudinal-integrated database for health insurance and labour market studies (LISA) of Statistics Sweden [43]. These registers include data for the entire Swedish population, and when linking data, this can strengthen the completeness of SNAR. Furthermore, SNAR also provides opportunities to study pharmacological treatment and comorbidities in relation to obstructive lung diseases, as well as the co-variation between asthma and COPD. Another important quality register aspect is the opportunity to include new data on short notice. For example, during the ongoing COVID-19 pandemic variables have been included to monitor the incidence of COVID-19 among registered asthma and COPD patients.

Clinical implications of SNAR include the opportunity to assess the effectiveness of public health interventions concerning asthma and COPD. SNAR is implemented in all counties in Sweden, and the majority of the data are directly transferred from EMRs to the registry. To ensure data transfer and to support the counties, synchronized templates are designed. Furthermore, data from 2019 indicate that adherence to guidelines has clear potential for improvements, and in particular, investigation of allergy and smoking cessation are areas of importance, but also patient education and the use of written action plans. Further, equal care is of importance, but data from SNAR indicate an issue in this regard, especially with regards to asthma, and such sex-differences in healthcare need to be better considered and rectified.

**Conclusion**

SNAR has cumulatively registered over 270,000 individuals and provides a unique insight into the care of patients with asthma and COPD in Sweden. The register is important for patients, caregivers, authorities, politicians and researchers to evaluate the impact of and adherence to local, national and international guidelines. The current analysis of data from 2019 gives an overview of the clinical characteristics of patients with asthma or
COPD in Swedish health care and suggests room for improvement for guideline adherence and quality of care.

Acknowledgments

Most importantly, acknowledgment is given to all the patients, physicians, nurses and others who continue to contribute data to SNAR. Further acknowledgements are given to the former and current register coordinators, and members in the steering committee. The county councils in Sweden are acknowledged for basic quality register financial support, and the Centre of Registers Västra Götaland for infrastructure and data management support. Special thanks to Bengt Bengtsson for statistical support. Further acknowledgment goes to the patient associations, The Swedish Asthma- and Allergy association and The Swedish Heart and Lung Association for a successful collaboration.

Disclosure statement

No potential conflict of interest was reported by the authors.

Funding

This work was supported by the Swedish Heart-Lung Foundation under Grant [20190183].

Notes on contributors

Caroline Stridsman is a respiratory nurse at Sunderby Hospital, Luleå and associate professor at Umeå University, Department of Public Health and Clinical Medicine, Sweden. Her field of research is epidemiological studies of asthma and COPD with focus on symptoms, health status, care and treatment. She is the chairman of the SNAR.

Jon Konradsen is a medical doctor and head of pediatric allergy and pulmonology at Astrid Lindgren Children’s Hospital, Karolinska University Hospital, Sweden. He is a research group leader at the Department of Women’s and Children’s Health at Karolinska Institutet, and his research is focused on diagnosis and management of asthma and allergy in childhood. He is a member of the steering committee of SNAR.

Lowe Vanfleteren is associate professor at the university of Gothenburg, respiratory physician and head of the COPD center at the Sahlgrenska University Hospital in Gothenburg, Sweden. His research and clinical experience relates to the understanding, management and organization of care of COPD. He is a member of the steering committee of SNAR.

Christophe Pedroletti is a child allergologist and PhD in the field of childhood asthma. Since 2018 he is the CEO of Södertälje General Hospital in Stockholm, Sweden. He is a member of the steering committee of SNAR.

Jonas Binnmyr is a PhD and patent organisation representative for The Swedish Asthma- and Allergy association. Patient organisations provides help to understand the experience of living with a disease or a condition. The patient organisations’ representatives have an important role in SNAR, providing a united voice to promote and advocate the best interests of the patients.

Peter Edfelt is a patent organisation representative for The Swedish Heart and Lung Association. Patient organisations provides help to understand the experience of living with a disease or a condition. The patient organisations’ representatives have an important role in SNAR, providing a united voice to promote and advocate the best interests of the patients.

Kerstin Fjällman Schärberg is a respiratory nurse and registry coordinator in SNAR, as well as a member of the steering committee.

Yvonne Sjöö is a respiratory nurse and registry coordinator in SNAR, as well as a member of the steering committee.

Fredrik Nyberg is Professor of Register Epidemiology at the School of Public Health and Community Medicine, Institute of Medicine, University of Gothenburg. His work is focused on epidemiological research based on register data of various kinds, as well as large-scale epidemiological investigations. Disease areas of interest include respiratory and cardiovascular/metabolic disease, autoimmune and joint diseases, and recently Covid-19. He is a member of the steering committee of SNAR.

Anne Lindberg is a medical doctor, senior lecturer and Associate Professor at Umeå university, Department of Public Health and Clinical Medicine, Sweden. Her research and clinical expertise relates to epidemiology and obstructive lung diseases, especially COPD. She is a member of the steering committee of SNAR.

Alf Tunsäter is Associate Professor at Department of Respiratory Medicine & Allergology, Skåne University Hospital, Lund, Sweden. He researches mainly in the area of asthma, allergy and COPD and has a special interest in Health Related Quality of Life in these diseases. He is a member of the steering committee of SNAR.

Ann Ekberg Jansson is a medical doctor and Associate Professor at Gothenburg University, Department of Internal Medicine and Clinical Nutrition, Sweden. Her research relates to obstructive lung diseases, especially COPD. She is also the former chairman of SNAR.

ORCID

C Stridsman @ http://orcid.org/0000-0001-6622-3838
L Vanfleteren @ http://orcid.org/0000-0002-4387-4096

References

[1] To T, Stanoevic S, Moores G, et al. Global asthma prevalence in adults: findings from the cross-sectional world health survey. BMC Public Health. 2012;19:12: 204–2458-12-204.
[2] Backman H, Raisanen P, Hedman L, et al. Increased prevalence of allergic asthma from 1996 to 2006 and
Further to 2016 results from three population surveys. Clin Exp Allergy. 2017;47:1426–1435.

[3] Akinbami LJ, Simon AE, Rossen LM. Changing trends in asthma prevalence among children. Pediatrics. 2016;137. DOI: 10.1542/peds.2015-2354.

[4] Hicke-Roberts A, Aberg N, Wennergren G, et al. Allergic rhinoconjunctivitis continued to increase in Swedish children up to 2007, but asthma and eczema levelled off from 1991. Acta Paediatr. 2017;106:75–80.

[5] Stridsman C, Backman H, Eklund BM, et al. Adolescent girls with asthma have worse asthma control and health-related quality of life than boys-A population based study. Pediatr Pulmonol. 2017;52:866–872.

[6] Backman H, Jansson SA, Stridsman C, et al. Severe asthma - A population study perspective. Clin Exp Allergy. 2019;49:819–828.

[7] Lang A, Carlsen KH, Haaland G, et al. Severe asthma in childhood: assessed in 10 year olds in a birth cohort study. Allergy. 2008;63:1054–1060.

[8] Public Health Agency of Sweden. Daily smoking. Available from: https://www.folkhalsomyndigheten.se/.

[9] Backman H, Eriksson B, Rönmark E, et al. Decreased prevalence of moderate to severe COPD over 15 years in northern Sweden. Respir Med. 2016;114:103–110.

[10] Eriksson B, Backman H, Ekerljung L, et al. Pattern of cardiovascular comorbidity in COPD in a country with low-smoking prevalence: results from two-population-based cohorts from Sweden. COPD. 2018;15(5):454–463.

[11] The Global Initiative for Chronic Obstructive Lung Disease (GOLD). Global strategy for the diagnosis, management, and prevention of chronic obstructive pulmonary disease. [updated 2020]. Available from: https://goldcopd.org/

[12] Global Initiative for Asthma (GINA). Global strategy for asthma management and prevention. [updated 2020]. Available from: http://www.ginasthma.org/.

[13] Lisspers K, Larsson K, Johansson G, et al. Economic burden of COPD in a Swedish cohort: the ARCTIC study. Int J Chron Obstruct Pulmon Dis. 2018;13:275–285.

[14] Jansson SA, Backman H, Rönmark E, et al. Hospitalization due to co-morbid conditions is the main cost driver among subjects with COPD-A report from the population-based OLIN COPD study. COPD. 2015;12:381–389.

[15] Jansson SA, Backman H, Andersson M, et al. Severe asthma is related to high societal costs and decreased health related quality of life. Respir Med. 2020;162:105860.

[16] Bahadori K, Doyle-Waters MM, Marra C, et al. Economic burden of asthma: a systematic review. BMC Pulm Med. 2009;19(9):24–2466-9-24.

[17] The Swedish National Airway Register. Available from: https://lvr.registercentrum.se/

[18] The National Board of Health and Welfare. National guidelines for asthma and COPD. [updated 2018]. Available from: www.socialstyrelsen.se

[19] Henoch I, Strang S, Löfdahl CG, et al. Health-related quality of life in a nationwide cohort of patients with COPD related to other characteristics. Eur Clin Respir J. 2016;27(3):31459.

[20] Henoch I, Löfdahl CG, Ekberg-Jansson A. Influences of patient education on exacerbations and hospital admissions in patients with COPD - a longitudinal national register study. Eur Clin Respir J. 2018;31(5):1500073.

[21] Henoch I, Strang S, Löfdahl CG, et al. Management of COPD, equal treatment across age, gender, and social situation? A register study. Int J Chron Obstruct Pulmon Dis. 2016;26(11):2681–2690.

[22] Sundh J, Ekström M. Risk factors for developing hypoxic respiratory failure in COPD. Int J Chron Obstruct Pulmon Dis. 2017;20(12):2095–2100.

[23] Swedish National Quality Registries. Available from: http://www.kvalitetsregister.se/englishpages.2040.html

[24] Graham BL, Steenbruggen I, Miller MR, et al. Standardization of spirometry 2019 update. an official American thoracic society and European respiratory society technical statement. Am J Respir Crit Care Med. 2019;200: e70–e88.

[25] Nathan RA, Sorkness CA, Kosinski M, et al. Development of the asthma control test: a survey for assessing asthma control. J Allergy Clin Immunol. 2004;113:59–65.

[26] Schatz M, Sorkness CA, Li JT, et al. Asthma control test: reliability, validity, and responsiveness in patients not previously followed by asthma specialists. J Allergy Clin Immunol. 2006;117:549–556.

[27] Liu AH, Zeiger R, Sorkness C, et al. Development and cross-sectional validation of the childhood asthma control test. J Allergy Clin Immunol. 2007;119:817–825.

[28] Jones PW, Harding G, Berry P, et al. Development and first validation of the COPD assessment test. Eur Respir J. 2009;34:648–654.

[29] Smid DE, Franssen FME, Gonik M, et al. Redefining cut-points for high symptom burden of the global initiative for chronic obstructive lung disease classification in 18,577 patients with chronic obstructive pulmonary disease. J Am Med Dir Assoc. 2017;18(18):1097.e111-1097.e24.

[30] Holland AE, Spruit MA, Troosters T, et al. An official European Respiratory Society/American Thoracic Society technical standard: field walking tests in chronic respiratory disease. Eur Respir J. 2014;44:1428–1446.

[31] Ferrara G, Carlson L, Palm A, et al. Idiopathic pulmonary fibrosis in Sweden: report from the first year of activity of the Swedish IPF-registry. Eur Clin Respir J. 2016;21(3):31090.

[32] Eliasson B, Cederholm J, Nilsson P, et al. Steering committee of the swedish national diabetes register. The gap between guidelines and reality: type 2 diabetes in a national diabetes register 1996–2003. Diabet Med. 2005;22:1420–1426.

[33] Zupanic E, Kareholt I, Norving B, et al. Acute stroke care in dementia: a cohort study from the swedish dementia and stroke registries. J Alzheimers Dis. 2018;66:185–194.

[34] Ek A, Ekblom O, Hambraeus K, et al. Physical inactivity and smoking after myocardial infarction as predictors for readmission and survival: results from the SWEDHEART-registry. Clin Res Cardiol. 2019;108:324–332.
[35] Aaron SD, Boulet LP, Reddel HK, et al. Underdiagnosis and overdiagnosis of asthma. Am J Respir Crit Care Med. 2018;198:1012–1020.

[36] Sandelowsky H, Natalishvili N, Krakau I, et al. COPD management by Swedish general practitioners - baseline results of the PRIMAIR study. Scand J Prim Health Care. 2018;36:5–13.

[37] Diab N, Gershon AS, Sin DD, et al. Underdiagnosis and overdiagnosis of chronic obstructive pulmonary disease. Am J Respir Crit Care Med. 2018;198:1130–1139.

[38] Jagorstrand B. Spirometriskörtet - teamutbildning och kvalitetssäkring. Allergi i PrakXsis. 2018;2:26–27.

[39] Tonnesen P. Smoking cessation and COPD. Eur Respir Rev. 2013;22:37–43.

[40] McLeish AC, Zvolensky MJ. Asthma and cigarette smoking: a review of the empirical literature. J Asthma. 2010;47:345–361.

[41] Yawn BP, Rank MA, Cabana MD, et al. Adherence to asthma guidelines in children, tweens, and adults in primary care settings: a practice-based network assessment. Mayo Clin Proc. 2016;91:411–421.

[42] The Swedish National Board of Health and Welfare. Statistical databases. Available from: https://www.socialstyrelsen.se/en/statistics-and-data/registers/

[43] Statistics Sweden. The longitudinal integrated database for health insurance and labour market studies (LISA). Available from: https://www.scb.se/