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The Swedish Pregnancy Register – for quality of care improvement and research

OLOF STEPHANSSON1,2, KERSTIN PETERSSON3,4, CAMILLA BJÖRK4, PETER CONNER2,5 & ANNA-KARIN WIKSTRÖM1,6

1Clinical Epidemiology Unit, Department of Medicine – Solna, Karolinska Institute, Stockholm, 2Department of Women’s and Children’s Health, Karolinska Institute, Stockholm, 3Department of Clinical Sciences, Obstetrics and Gynecology, Umeå University, Umeå, 4Department of Healthcare Development, Public Health Care Services Committee, Stockholm County Council, Stockholm, 5Center for Fetal Medicine, Karolinska University Hospital, Stockholm, and 6Department of Women’s and Children’s Health, Uppsala University, Uppsala, Sweden

Abstract

Introduction. The objective of this study was to present the Swedish Pregnancy Register and to explore regional differences in maternal characteristics, antenatal care, first trimester combined screening and delivery outcomes in Sweden. Material and methods. The Pregnancy Register (www.graviditetsregistret.se) collects data on pregnancy and childbirth, starting at the first visit to antenatal care and ending at the follow-up visit to the antenatal care, which usually occurs at around 8–16 weeks postpartum. The majority of data is collected directly from the electronic medical records. The Register includes demographic, reproductive and maternal health data, as well information on prenatal diagnostics, and pregnancy outcome for the mother and the newborn. Results. Today the Register covers more than 90% of all deliveries in Sweden, with the aim to include all deliveries within 2018. The care providers can visualize quality measures over time and compare results with other clinics, regionally and nationally by creating reports on an aggregated level or using case-mix adjusted Dash Boards in real time. Detailed data can be extracted after ethical approval for research. In this report, we showed regional differences in patient characteristics, antenatal care, fetal diagnosis and delivery outcomes in Sweden. Conclusions. Our report indicates that quality in antenatal and delivery care in Sweden varies between regions, which warrants further actions. The Swedish Pregnancy Register is a new and valuable resource for benchmarking, quality improvement and research in pregnancy, fetal diagnosis and delivery.

Abbreviations: EMR, electronic medical record; FTS, first trimester screening.

Introduction

In Sweden there are approximately 115 000 births annually. Antenatal care is free of charge, and almost all women attend. The antenatal care is organized in defined areas, usually including all antenatal care units of the catchment area of a specified hospital. Each area has an antenatal care obstetrician and a midwife coordinator, who are responsible for evaluating and improving quality of care. Midwives are the main providers of antenatal care, with a referral system to obstetricians when needed. The first visit to antenatal care is usually around
gestational week 9 and the national guidelines recommend a minimum of eight visits during pregnancy. Additionally, a visit eight to 12 weeks postpartum is offered. In Sweden, all pregnant women are routinely offered a second trimester ultrasound scan that generally is performed by specially trained midwives. There are no uniform national guidelines concerning trisomy testing; policies vary in different regions and have been changing continuously during the last decade and range from first trimester screening (FTS) for all women independent of age to only invasive testing for women above 35 years of age. Home deliveries are rare in Sweden (<1%). Today there are 42 delivery hospitals, responsible for between 500 and 8500 deliveries annually. Antenatal and ultrasound electronic medical records are shared with hospital delivery records within each region.

To promote improved quality of care in pregnancy and childbirth, the Swedish Pregnancy Register (www.gravidregistret.se) was started in 2013 by merging the Maternal Health Care Register (1,2) (established in 1999) and the National Quality Register for Prenatal Diagnosis (3,4) (established in 2006) and by initiation of collecting information from deliveries. Today the Pregnancy Register includes data on pregnancy and childbirth, starting at the first visit to antenatal care, where demographic, reproductive and maternal health data are collected. Thereafter information from ultrasound examinations in the first and second trimester as well as fetal growth assessments, complications during pregnancy and delivery and of the newborn are collected. Data collection ends at the follow-up visit to the antenatal care, which usually occurs at around 8–16 weeks postpartum. The majority of data is collected directly from the electronic medical records (EMR).

There are three working groups: antenatal care, obstetrical ultrasound and delivery care and these are coordinated by a director and a steering group with representatives from the Swedish regions and medical universities as well as the Swedish Midwife Association and the Swedish Society for Obstetrics and Gynecology.

Sweden and the Nordic countries have a long tradition of Medical Birth Registers. Since the start, data from the Swedish Medical Birth Register, including approximately 110 000 births annually, have shown a large variation in procedures and outcomes in pregnancy and childbirth between regions and delivery hospitals (5,6). The Swedish Medical Birth Register has the status of a health data register, managed by the authorities. Contributing with data is mandatory for the individual patient as well as for healthcare services. These regulations imply some restrictions in how data may be used by healthcare providers for benchmarking and quality improvement. There is a time lag in data availability in the Swedish Medical Birth Register and it is not possible to obtain individual data on treated patients for healthcare providers without ethical approval.

Material and methods

The policy is that no data should be registered more than once by the caregivers in pregnancy and delivery care. The Pregnancy Register receives data from three different sources:

1. Manually web-entered data by antenatal care midwives at registration to antenatal care for variables that are not registered in the EMRs. This includes information on Country of birth, level of education, main occupation, self-rated health before pregnancy. At the follow-up visit between eight and 16 weeks postpartum, the antenatal care midwife enters data on prenatal diagnosis, use of professional translator, parent support attendance, support for fear of childbirth, treatment of psychiatric disorders, screening for intimate partner violence, oral glucose test values, diagnosis of gestational diabetes, physician attendance in antenatal care, maternal weight postpartum, breast feeding at four weeks postpartum and self-reported health during and after pregnancy. In addition to individual data, antenatal care units annually report data on structure and organization, including specified guidelines, for example on gestational diabetes and offers for prenatal diagnosis.

2. Information on first trimester combined ultrasound and biochemistry examinations for detection of chromosomal anomalies (3). The web-based system uses an algorithm based on likelihood ratios of established serum markers including free beta subunit of human chorionic gonadotropin, and pregnancy-associated plasma protein A and nuchal translucency from Gaussian distributions in normal and affected pregnancies (4). The first trimester risk assessment system is available for certified units and users throughout the country.

3. Electronic transfer of data from the EMRs from 2013 and onwards. Figure 1 displays the three EMRs in use in Sweden at present. Currently, there is a direct transfer within 24 h after birth from all counties using the Obstetrix® system (90% of all deliveries in Sweden). We are testing transfer of data from Cosmic Birth® in Uppsala county (we will carry on with the counties of Värmland and Kronoberg thereafter) and Partus® in Norrbotten county. The ambition is to include these counties by 2018. The data transfer includes some 220 variables, from antenatal care, biometry data from second trimester routine scans and fetal weight estimations to data on delivery and
postpartum care for the mother and infant including diagnoses and procedures.

A complete variable list is presented as a Supporting Information Appendix S1. The Pregnancy register collects and store data using the unique Swedish personal registration number for both mother and infant as the primary key (7). There is also a secondary key to link mother and infant in the Register. All pregnant women are informed that data from antenatal care, ultrasound examinations and delivery are recorded in the registry, with the possibility to opt out at any time (<1% of all births annually).

For Tables 1 and 4 we present data for all counties with direct transfer of EMR data in 2014–2015. The North region includes Västerbotten, Jämtland & Härjedalen and Västernorrland, the Central region includes Dalarna, Västmanland, Örebro, Sörmland and Gävleborg, the Capital includes Stockholm and Gotland, the South East includes Östergötland, Kalmar and Jönköping, the South region includes Skåne, Blekinge and Halland, and the West region includes Västra Götaland. For Tables 2 and 3 we present data on detection rates of chromosomal anomalies on first trimester combined ultrasound and biochemistry examinations from 2006 and onwards.

Today there are three ways to explore data in the Register. First, databases based on individual data from each clinic can be created for statistical analyses. Secondly, the Register provides aggregated data for reports where the care provider can visualize quality measures and compare results with other clinics, regionally and nationally. This report system enables the care providers

![Figure 1. Electronic medical record systems in antenatal care and delivery in Sweden 2017 by county/region.](image-url)
Table 1. Maternal characteristics for births in 2014–2015 by Swedish region.

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<th>Region</th>
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<th>Capital</th>
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<td>431 (1.5)</td>
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<td>142 (1.2)</td>
<td>539 (2.1)</td>
<td>337 (0.6)</td>
<td>389 (1.4)</td>
<td>310 (1.4)</td>
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<td>671</td>
<td>2518</td>
<td>473</td>
<td>2250</td>
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</tbody>
</table>

BMI (kg/m²)

| <18.5 (%) | 294 (2.6) | 649 (2.5) | 1710 (3.0) | 728 (2.6) | 529 (2.5) | 933 (2.6) | 4843 (2.7) |
| 18.5 ≤ 25 (%) | 6401 (56.1) | 13342 (52.2) | 37066 (64.9) | 16491 (59.5) | 12048 (55.9) | 20729 (58.1) | 106077 (59.2) |
| 25 ≤ 30 (%) | 3008 (26.4) | 7039 (27.5) | 12728 (22.3) | 6933 (25.0) | 5792 (26.9) | 9361 (26.2) | 44861 (25.0) |
| 30 ≤ 35 (%) | 1158 (10.1) | 3097 (12.1) | 4194 (7.3) | 2520 (9.1) | 2257 (9.2) | 330 (0.9) | 16523 (9.2) |
| ≥35 (%) | 149 (1.3) | 399 (1.6) | 320 (0.6) | 265 (1.0) | 219 (1.0) | 370 (1.0) | 1722 (1.0) |
| Missing | 692 | 1619 | 2284 | 3186 | 701 | 3171 | 11653 |

Mean (SD) 25.2 (6.9) 25.6 (5.1) 24.1 (4.3) 24.7 (4.7) 25.1 (4.8) 24.9 (7.5) 24.7 (5.5)

Median (25th – 75th) 24.0 (21.7 – 27.4) 24.5 (22.0 – 28.2) 23.1 (21.1 – 26.0) 23.7 (21.5 – 27.0) 24.0 (21.7 – 27.5) 23.9 (21.6 – 27.1) 23.7 (21.5 – 27.0)

Weight gain (kg), mean (SD)

| BMI <18.5 | 12.8 (4.6) | 12.6 (4.6) | 12.4 (4.3) | 13.1 (4.3) | 12.2 (4.2) | 12.6 (4.5) | 12.6 (4.4) |
| BMI 18.5 ≤ 25 | 13.4 (4.7) | 13.2 (4.9) | 13.0 (4.7) | 13.7 (4.8) | 13.0 (4.6) | 13.3 (4.8) | 13.2 (4.8) |
| BMI 25 ≤ 30 | 13.1 (5.5) | 12.7 (5.7) | 12.5 (5.5) | 13.1 (5.8) | 12.5 (5.4) | 12.9 (5.7) | 12.8 (5.6) |
| BMI 30 ≤ 35 | 11.8 (5.8) | 11.2 (6.1) | 10.9 (5.8) | 11.1 (6.2) | 10.8 (5.7) | 11.3 (5.9) | 11.1 (5.9) |
| BMI 35 ≤ 40 | 9.6 (5.6) | 10.0 (6.3) | 9.6 (5.5) | 9.9 (6.0) | 10.1 (5.8) | 9.8 (5.9) | 9.8 (5.9) |
| BMI ≥40 | 8.5 (5.0) | 9.2 (5.9) | 8.6 (5.5) | 8.9 (5.4) | 9.5 (5.4) | 9.4 (5.5) | 9.1 (5.6) |
| Overall | 13.0 (5.2) | 12.6 (5.4) | 12.6 (5.0) | 13.2 (5.3) | 12.5 (5.1) | 12.9 (5.3) | 12.8 (5.2) |
| Missing | 10.8 (6.5) | 9.0 (5.3) | 10.8 (4.7) | 10.0 (5.8) | 11.8 (6.3) | 11.9 (6.4) | 10.7 (5.8) |

Smoking at registration at antenatal care (%)

| Yes | 376 (3.2) | 1658 (24.5) | 2112 (3.7) | 1529 (5.4) | 1288 (10.2) | 2540 (7.2) | 9503 (6.3) |
| No | 541 (4.5) | 387 (1.8) | 578 (1.0) | 271 (0.9) | 211 (1.2) | 202 (0.5) | 2190 (1.2) |

Snuff use at registration at antenatal care (%)

| Yes | 312 (2.9) | 690 (2.7) | 3573 (6.1) | 947 (3.8) | 547 (2.6) | 778 (2.6) | 6847 (4.0) |
| No | 3094 (29.3) | 5966 (24.4) | 16347 (31.3) | 6617 (24.6) | 5958 (30.0) | 11164 (31.8) | 49146 (29.1) |

In vitro fertilization (%)

| Yes | 5536 (52.4) | 13172 (53.8) | 26066 (50.0) | 14046 (52.2) | 10151 (51.1) | 19099 (54.1) | 87980 (52.0) |
| No | 738 (7.0) | 1850 (7.6) | 3229 (6.2) | 1738 (6.5) | 1249 (6.3) | 2100 (6.0) | 10904 (6.4) |

Self-reported health prior to pregnancy (%)

| Very good | 3094 (29.3) | 5966 (24.4) | 16347 (31.3) | 6617 (24.6) | 5958 (30.0) | 11164 (31.8) | 49146 (29.1) |
| Good | 5536 (52.4) | 13172 (53.8) | 26066 (50.0) | 14046 (52.2) | 10151 (51.1) | 19099 (54.1) | 87980 (52.0) |
| Neither good or bad | 738 (7.0) | 1850 (7.6) | 3229 (6.2) | 1738 (6.5) | 1249 (6.3) | 2100 (6.0) | 10904 (6.4) |
| Poor | 193 (1.8) | 574 (2.3) | 947 (1.8) | 569 (2.1) | 343 (1.7) | 724 (2.1) | 3350 (2.0) |
| Very poor | 29 (0.3) | 148 (0.6) | 227 (0.4) | 152 (0.6) | 95 (0.5) | 164 (0.5) | 815 (0.5) |
| Unknown | 974 (9.2) | 2764 (11.3) | 5334 (10.2) | 3801 (14.1) | 2069 (10.4) | 1997 (5.7) | 16939 (10.0) |
| Missing | 1539 | 2699 | 7282 | 3995 | 2406 | 3703 | 21624 |

Self-reported health during pregnancy (%)
Table 1. Continued

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<th>Region</th>
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<th>South East</th>
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<td>Self-reported health after pregnancy (%)</td>
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<td>1314</td>
<td>520</td>
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to create personal reports, and templates of reports are provided. Thirdly, by the use of dashboards (Power BI®; Microsoft Corp., Redmond, WA, USA), the Register provides a possibility to obtain case-mix adjusted results in real time, which facilitates comparisons between clinics with differences in baseline characteristics of the pregnant population. In the case-mix we adjust for maternal and pregnancy characteristics at first registration to antenatal care including: maternal age, body mass index, height, cigarette smoking, parity, previous cesarean delivery, country of birth, education, in vitro fertilization and comorbidities. By adjusting for these variables, we can control for differences in patient characteristics when comparing outcomes for delivery clinics. There are also dashboards where results can be followed over time. However, the number of dashboards is limited, focusing on results that are most common to benchmark, for example mode of delivery and incidence of severe lacerations. Further, the Register has public dashboards.

The Pregnancy Register has set target measures for quality in antenatal and delivery care. The target measures for antenatal care are 95% for screening with alcohol AUDIT and for domestic violence and 85% for postpartum visit to antenatal care. For delivery, each target is set as the cut-off for the best 20% clinics in 2014–2015. The target are as follows: 80% non-instrumental vaginal delivery, 5.5% postpartum hemorrhage (>1000 mL) for vaginal delivery and 12% for cesarean delivery, 8.7% obstetric anal sphincter injury in instrumental and 1.9% non-instrumental vaginal delivery, respectively. The target for cesarean delivery in the Robson 1 group (primiparous, singleton, cephalic, term delivery with spontaneous onset) (8), is set at 6%. The target values have been processed in the working groups of the Register, containing midwives and doctors from all regions of Sweden. For prenatal diagnosis by combined FTS, yearly audits are performed with requirements of all ultrasound operators and biochemistry laboratories that 40–60% of nuchal translucency measurements are above the median and that first trimester biomarkers are within ±10% of median MoM values.

The Pregnancy Register has developed a protocol with manually web-entered data for categorization of cause of death for stillbirth (gestational week 22 and onwards), which can be used in clinical practice. The protocol includes data that are not retrievable from the standardized antenatal, obstetric and neonatal records and which are based on the Stockholm Classification of Stillbirth (9).

After ethical approval, researchers affiliated to Swedish universities may obtain de-identified data from the Register where linkages with other national and quality registers are possible. The Pregnancy Register provides the
infrastructure and data collection for a national randomized controlled trial on labor induction in gestational week 41 compared with the Swedish gold standard; gestational week 42 (10). By providing the infrastructure including web-based randomization and data collection for randomized controlled trials, the Pregnancy Register reduces costs and increases collaboration between delivery hospitals in Sweden.

Results

Table 1 displays maternal characteristics in births in 2014–2015 by region. Mean age at delivery was 30.9 years, and mean body mass index at first attendance to antenatal care 24.7 kg/m². Approximately one in four women were born outside of Sweden. Only 5.0% were cigarette smokers and 1.2% used Swedish snuff. The proportion of in vitro fertilization pregnancies was 3.7%. Self-reported health was lowest during pregnancy and tended to be reduced after compared with before pregnancy. The proportion of women screened for intimate partner violence was 77.2%. Only 1.7% were diagnosed with gestational diabetes, and 11.7% received treatment for a psychiatric disorder during pregnancy. In all, 64.3% of the women had a follow-up visit after childbirth at antenatal care and 80.9% reported breastfeeding at discharge from the delivery hospital.

Table 2. Detection rates of chromosomal anomalies and positive test ratios after combined first trimester screening (FTS), 2006–2014.

<table>
<thead>
<tr>
<th></th>
<th>Nuchal translucency</th>
<th>%</th>
<th>Combined FTS</th>
<th>%</th>
<th>Test positive %</th>
</tr>
</thead>
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<tr>
<td>Trisomy 21, n = 653</td>
<td>471/653</td>
<td>72</td>
<td>579/653</td>
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<td>Trisomy 18, n = 222</td>
<td>119/179</td>
<td>66</td>
<td>155/279</td>
<td>87</td>
<td>0.6</td>
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<td>71</td>
<td>57/72</td>
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<td>Triploidy, n = 35</td>
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<td>69</td>
<td>35/35</td>
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<td>Turner syndrome, n = 46</td>
<td>39/46</td>
<td>85</td>
<td>42/46</td>
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<tr>
<td>Total, n = 985</td>
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<td>71</td>
<td>868/985</td>
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Table 3. Detection rates of chromosomal anomalies and positive test ratios after combined first trimester screening (FTS), 2015.

<table>
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<th>%</th>
<th>Combined FTS</th>
<th>%</th>
<th>Test positive %</th>
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<td>77</td>
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<td>70</td>
<td>36/43</td>
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<td>Total, n = 209</td>
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<td>73</td>
<td>187/209</td>
<td>89</td>
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Table 2. Detection rates of chromosomal anomalies and positive test ratios after combined first trimester screening (FTS), 2006–2014.

of 653 pregnancies with trisomy 21 were detected after screening (89%); the corresponding proportion for 2015 was 121 of 131 pregnancies with Trisomy 21 (92%). Detection rates of Trisomy 18 and 13 were 87 and 79%, respectively, in 2006–2014. For 2015, the detection rates were 84 and 67%, respectively. The detection of pregnancies with triploidy was 100% for both time periods.

Delivery outcomes by region in 2014–2015 are presented in Table 4. The proportion of cesarean delivery was 17.6% and of vacuum extraction 6.1%. Preterm birth before 37 completed weeks was reported in 5.7% of births. The rate of postpartum hemorrhage (>1000 mL) was 5.7% in vaginal deliveries and 12.8% in cesarean deliveries. Obstetric anal sphincter injury (grade III–IV) was reported in 2.8% of non-instrumental vaginal delivery and 12.8% in instrumental delivery. There were 619 stillbirths (0.4%) from gestational week 22 and onwards. Cord samples were reported in 82.6% of all births and for 71.7% of births with 5-min Apgar score <7. Delivery experience was obtained for 44.9% of all women using a scale from 1 to 10 where 10 is the best possible and 1 the worst experience. A majority of women reported an experience of 7–10 (84.4%), 12.1% a score between 4 and 6, and 3.5% a score between 1 and 3.

Discussion

The Swedish Pregnancy Register makes it possible to measure quality of care and outcomes of pregnancy and childbirth in Sweden. There are large differences in procedures and outcomes between regions. Care providers can follow their own results over time. Further, by case-mix
adjusted results, care providers can benchmark themselves with other delivery hospitals, regions and the nation. Results are presented using modern business formats with dashboards always showing updated results for care providers and for patients and the public. Furthermore, each health care provider has the opportunity to download their own data for internal quality analysis.

Today, Sweden has around 100 certified National Quality Registers created to enhance the quality of health care by collection and monitoring of quality measures for the healthcare providers and to be a foundation of a data resource for medical research. A National Quality Register contains individualized patient data including patient characteristics, procedures, and outcomes; within all healthcare sectors. The members of the steering committees of the Quality Registers are predominantly the health professionals, i.e. the healthcare providers. Quality Registers are monitored annually and approved for financial

<table>
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<th>Measure</th>
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<th>Central (%):</th>
<th>Capital (%):</th>
<th>West (%):</th>
<th>South East (%):</th>
<th>South (%):</th>
<th>Total (%):</th>
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<td>Cesarean section</td>
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<td>33 000 (17.3)</td>
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<td>&lt;32</td>
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<td>222 (0.8)</td>
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<td>359 (1.2)</td>
<td>218 (1.0)</td>
<td>379 (1.0)</td>
<td>1887 (1.0)</td>
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<td>561 (4.6)</td>
<td>1384 (5.1)</td>
<td>2657 (4.5)</td>
<td>1464 (4.7)</td>
<td>1029 (4.6)</td>
<td>1943 (5.0)</td>
<td>9020 (4.7)</td>
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<tr>
<td>≥37</td>
<td>11 395 (94.2)</td>
<td>25 567 (94.1)</td>
<td>56 212 (94.6)</td>
<td>29 104 (94.1)</td>
<td>21 021 (94.4)</td>
<td>36 535 (94.0)</td>
<td>179 834 (94.3)</td>
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<tr>
<td><strong>Induction of labor</strong></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Yes</td>
<td>2039 (16.8)</td>
<td>4440 (16.3)</td>
<td>11 541 (19.4)</td>
<td>4603 (14.9)</td>
<td>3770 (16.9)</td>
<td>6485 (16.7)</td>
<td>32 878 (17.2)</td>
</tr>
<tr>
<td>Of which ended in cesarean section</td>
<td>357 (2.5)</td>
<td>799 (3.0)</td>
<td>2203 (3.9)</td>
<td>840 (2.4)</td>
<td>1146 (4.7)</td>
<td>5876 (16.7)</td>
<td>32 878 (17.2)</td>
</tr>
<tr>
<td><strong>5-min Apgar scores, term pregnancies</strong></td>
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<td></td>
<td></td>
<td></td>
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<tr>
<td>0–3</td>
<td>43 (0.4)</td>
<td>153 (0.6)</td>
<td>327 (0.6)</td>
<td>130 (0.4)</td>
<td>85 (0.4)</td>
<td>200 (0.5)</td>
<td>938 (0.5)</td>
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<tr>
<td>4–6</td>
<td>174 (1.5)</td>
<td>384 (1.4)</td>
<td>475 (0.8)</td>
<td>304 (1.0)</td>
<td>237 (1.1)</td>
<td>364 (0.9)</td>
<td>1938 (1.0)</td>
</tr>
<tr>
<td>7–10</td>
<td>11 777 (98.2)</td>
<td>26 462 (98.0)</td>
<td>58 442 (98.6)</td>
<td>30 225 (98.6)</td>
<td>21 773 (98.5)</td>
<td>38 146 (98.5)</td>
<td>186 825 (98.5)</td>
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<tr>
<td>Missing</td>
<td>109</td>
<td>174</td>
<td>188</td>
<td>259</td>
<td>176</td>
<td>151</td>
<td>1057</td>
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<tr>
<td><strong>Postpartum hemorrhage &gt;1000 mL</strong></td>
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<tr>
<td>Cesarean delivery</td>
<td>225 (11.9)</td>
<td>692 (15.3)</td>
<td>1692 (13.3)</td>
<td>674 (14.0)</td>
<td>336 (11.1)</td>
<td>689 (11.3)</td>
<td>4308 (13.0)</td>
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<td>Vaginal delivery</td>
<td>487 (4.8)</td>
<td>1148 (5.1)</td>
<td>3486 (7.5)</td>
<td>1945 (7.5)</td>
<td>880 (4.6)</td>
<td>1564 (4.8)</td>
<td>9510 (6.0)</td>
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<tr>
<td><strong>Obstetric anal sphincter injury</strong></td>
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<td></td>
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</tr>
<tr>
<td>Non-instrumental delivery</td>
<td>239 (2.5)</td>
<td>466 (2.2)</td>
<td>1526 (3.6)</td>
<td>534 (2.2)</td>
<td>439 (2.4)</td>
<td>734 (2.4)</td>
<td>3938 (2.7)</td>
</tr>
<tr>
<td>Instrumental delivery</td>
<td>85 (110)</td>
<td>170 (10.5)</td>
<td>551 (14.2)</td>
<td>134 (9.2)</td>
<td>138 (11.5)</td>
<td>265 (10.9)</td>
<td>1343 (11.8)</td>
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<tr>
<td>Stillbirth</td>
<td>43 (0.4)</td>
<td>114 (0.4)</td>
<td>210 (0.3)</td>
<td>131 (0.4)</td>
<td>120 (0.5)</td>
<td>131 (0.3)</td>
<td>749 (0.4)</td>
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<tr>
<td><strong>Cord pH sampling</strong></td>
<td></td>
<td></td>
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<td></td>
<td></td>
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<tr>
<td>Overall</td>
<td>10 938 (90.4)</td>
<td>25 007 (92.0)</td>
<td>43 414 (73.0)</td>
<td>26 183 (84.7)</td>
<td>21 325 (95.8)</td>
<td>31 410 (80.8)</td>
<td>158 277 (83.0)</td>
</tr>
<tr>
<td>Proportion for Apgar &lt;7</td>
<td>175 (80.6)</td>
<td>432 (80.4)</td>
<td>521 (65.0)</td>
<td>329 (75.8)</td>
<td>283 (87.9)</td>
<td>342 (60.6)</td>
<td>2082 (72.4)</td>
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<tr>
<td><strong>Self-reported delivery experience</strong></td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1–3</td>
<td>107 (4.0)</td>
<td>253 (4.5)</td>
<td>744 (3.2)</td>
<td>88 (4.7)</td>
<td>179 (3.0)</td>
<td>1371 (3.5)</td>
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<tr>
<td>4–6</td>
<td>398 (15.0)</td>
<td>869 (15.6)</td>
<td>2498 (10.8)</td>
<td>339 (18.2)</td>
<td>751 (12.5)</td>
<td>4855 (12.4)</td>
<td></td>
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<tr>
<td>7–10</td>
<td>2151 (81.0)</td>
<td>4463 (79.9)</td>
<td>19 834 (86.0)</td>
<td>1433 (77.0)</td>
<td>5061 (84.5)</td>
<td>32 942 (84.1)</td>
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<tr>
<td>Missing</td>
<td>4255</td>
<td>9921</td>
<td>6700</td>
<td>15 171</td>
<td>13 709</td>
<td>49 756</td>
<td></td>
</tr>
</tbody>
</table>

The North region includes Västerbotten, Jämtland-Härjedalen and Västernorrland, the Central region includes Dalarna, Västmanland, Örebro, Sörmland and Gävleborg, the Capital includes Stockholm and Gotland, the West region includes Västra Götaland, the South East region includes Östergötland, Kalmar and Jönköping and the South region includes Skåne, Blekinge and Halland. Unknown refers to not known at time of postnatal web-entered data in antenatal care, whereas missing refers to women with no postnatal web-entered data in antenatal care.

*Deliveries during 2015 and not including Blekinge, Jönköping, Kalmar or Östergötland.*
support by an Executive Committee. According to the Swedish Patient Data Act, (11) patients are entitled to opt out from national quality registers, which does not apply for national health registers held by the National Board of Health and Welfare. Hence, the Register will not include data on all deliveries in Sweden. However, the proportion of women who choose to opt out is marginal.

In Sweden, approximately 70% of all FTS examinations for chromosomal anomalies are performed using the web-based algorithm in the Pregnancy Register. Midwives and obstetricians performing the ultrasound examinations are evaluated annually and those who do not fulfill the quality criteria are offered training in specialized fetal medicine units to be able to continue to use the registry software. The biochemistry laboratories performing the analysis of free beta subunit of human chorionic gonadotropin and pregnancy-associated plasma protein A are also evaluated annually and the quality has improved since the screening program started. Detection rates in our FTS program are ascertained by checking on cases of liveborn children with chromosomal anomalies with data from all of the six genetic laboratories in the country and are similar to those reported by other centers using alternative software programs (12,13). The working group for prenatal diagnosis and obstetrical ultrasound is currently setting up a system for quality control of second trimester screening examinations as well as growth estimations performed close to delivery.

The Pregnancy Register provides a platform for research with register-based randomized controlled trials (10) and perinatal outcomes research using the Register database after ethical approval. Because the Register includes data transferred directly from the EMRs, data are not entered twice by midwives and doctors. However, our experience is that structuring the EMR data requires extensive knowledge about the EMRs and close collaboration with the regional care and IT organizations as well as the companies maintaining the EMRs. At present the national coverage in the Pregnancy Register is more than 90% and continuously improving with the aim to include all antenatal care, fetal diagnostics and delivery clinics in Sweden. The goal for the Register is that the manually web-entered data by midwives in antenatal care (Appendix S1) will be reduced as we promote their introduction into the EMRs. Web-entered data by antenatal care midwives have been validated with good (70–94%) or very good (≥95%) agreement with medical records (2). The majority of variables in the Pregnancy Register are electronically transferred by the EMRs and because this is medical record data, we have validated variables and data transfer locally at participating clinics. In an external validation with the Medical Birth Register for deliveries in 2015, the coverage was 98–100% for counties with direct transfer of data from the EMRs.

The Pregnancy Register has rapidly become a tool in local assessment of provided care and quality improvement, for example in projects aiming to reduce the amount of severe laceration during labor or to increase attendance to the follow-up visit after childbirth at antenatal care.

The data in Pregnancy Register has many similarities with the data included in the Medical Birth Register. However, besides providing data in real time, the Pregnancy Register also supplies an additional 15% of variables compared with the Swedish Medical Birth Register. Examples of additional variables are educational level, country of birth, alcohol AUDIT, umbilical cord blood samples, self-reported health before, during and after delivery, and delivery experience.

In conclusion, the Swedish Pregnancy Register offers new possibilities for quality improvement in pregnancy and childbirth and research. The Pregnancy Register will provide updated results with case-mix adjustments that can be used in the definition of new or updated target values and guidelines and in debates on the organization of health care services. The goal is to increase equality and quality of care during pregnancy and delivery in Sweden.

Funding

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References


Supporting information

Additional Supporting Information may be found in the online version of this article:

Appendix S1. List of variables in the Swedish Pregnancy Register.