



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

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## Key words

Pregnancy register, pregnancy, prenatal care, prenatal diagnosis, delivery, training

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## Conflict of interest

The authors have stated explicitly that there are no conflicts of interest in connection with this article.

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## Abstract

**Introduction.** The objective 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](http://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

## Key Message

The Swedish Pregnancy Register is used for improvement in quality of care and research.

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.graviditetsregistret.se](http://www.graviditetsregistret.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

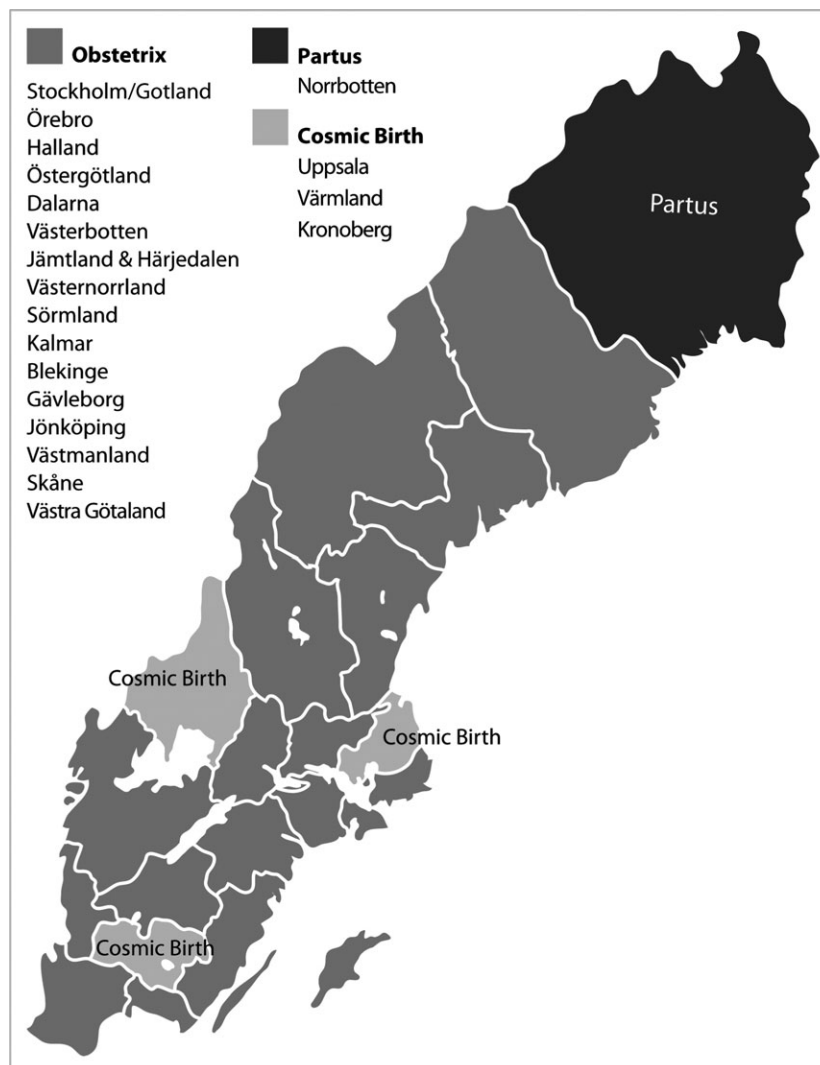
postpartum care for the mother and infant including diagnoses and procedures.

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.

**Table 1.** Maternal characteristics for births in 2014–2015 by Swedish region.

	Region						Total
	North	Central	Capital	West	South East	South	
<i>n</i>	12 103	27 173	59 432	30 918	22 271	38 861	190 758
Year (%)							
2014	5192 (42.9)	11 667 (42.9)	29 656 (49.9)	13 887 (44.9)	10 339 (46.4)	17 614 (45.3)	88 355 (46.3)
2015	6911 (57.1)	15 506 (57.1)	29 776 (50.1)	17 031 (55.1)	11 932 (53.6)	21 247 (54.7)	102 403 (53.7)
Age							
<20 (%)	176 (1.5)	469 (1.7)	414 (0.7)	306 (1.0)	345 (1.5)	500 (1.3)	2210 (1.2)
20 ≤ 25 (%)	1837 (15.2)	4609 (17.0)	4751 (8.0)	3640 (11.8)	3364 (15.1)	4965 (12.8)	23 166 (12.1)
25 ≤ 30 (%)	4097 (33.9)	9408 (34.7)	15 280 (25.7)	9849 (31.9)	7973 (35.8)	12 457 (32.1)	59 064 (31.0)
30 ≤ 35 (%)	3793 (31.4)	8038 (29.6)	22 172 (37.3)	10 737 (34.7)	6795 (30.5)	12 861 (33.1)	64 396 (33.8)
35 ≤ 40 (%)	1819 (15.0)	3726 (13.7)	13 244 (22.3)	5168 (16.7)	3076 (13.8)	6661 (17.1)	33 694 (17.7)
≥40 (%)	372 (3.1)	897 (3.3)	3561 (6.0)	1212 (3.9)	712 (3.2)	1404 (3.6)	8158 (4.3)
Missing	9	26	10	6	6	13	70
Mean (SD)	30.1 (5.1)	29.8 (5.2)	32.0 (5.1)	30.8 (5.1)	29.9 (5.1)	30.6 (5.2)	30.9 (5.2)
Median (25 <sup>th</sup> –75 <sup>th</sup> )	29.8 (26.3–33.7)	29.5 (25.9–33.4)	32.0 (28.5–35.4)	30.7 (27.2–34.3)	29.7 (26.3–33.4)	30.5 (26.9–34.2)	30.8 (27.1–34.4)
Level of education (%)							
Less than 9 years	71 (0.7)	306 (1.3)	133 (0.3)	194 (0.7)	101 (0.5)	175 (0.5)	980 (0.6)
9 ≤ 12 years	648 (6.1)	2298 (9.4)	2826 (5.4)	1942 (7.2)	1326 (6.7)	2559 (7.3)	11 599 (6.9)
12 years	4570 (43.2)	10 282 (42.0)	13 725 (26.3)	9336 (34.6)	8151 (41.0)	13 431 (38.2)	59 495 (35.2)
University	4657 (44.0)	8600 (35.1)	28 395 (54.4)	11 912 (44.1)	7852 (39.5)	16 442 (46.7)	77 858 (46.0)
Unknown	628 (5.9)	2989 (12.2)	7073 (13.6)	3615 (13.4)	2439 (12.3)	2582 (7.3)	19 326 (11.4)
Missing	1529	2698	7280	3919	2402	3672	21 500
Country of birth (%)							
Sweden	9001 (86.0)	18 487 (76.3)	36 902 (71.6)	20 030 (75.4)	15 629 (79.9)	26 202 (75.7)	126 251 (75.6)
Other Nordic countries	68 (0.6)	120 (0.5)	563 (1.1)	176 (0.7)	59 (0.3)	471 (1.4)	1457 (0.9)
Other European countries	315 (3.0)	1071 (4.4)	4510 (8.7)	1872 (7.1)	1144 (5.8)	3014 (8.7)	11 926 (7.1)
Other	1084 (10.4)	4547 (18.8)	9579 (18.6)	4475 (16.9)	2727 (13.9)	4925 (14.2)	27 337 (16.4)
Missing	1635	2948	7878	4365	2712	4249	23 787
Occupation (%)							
Employed	7662 (72.4)	15 498 (63.3)	38 557 (73.9)	18 289 (67.7)	13 622 (68.5)	24 137 (68.6)	117 765 (69.6)
Parental leave	692 (6.5)	2137 (8.7)	3692 (7.1)	2529 (9.4)	1616 (8.1)	2674 (7.6)	13 340 (7.9)
Sick leave	264 (2.5)	576 (2.4)	773 (1.5)	515 (1.9)	372 (1.9)	673 (1.9)	3173 (1.9)
Student	1165 (11.0)	3447 (14.1)	4851 (9.3)	3252 (12.0)	2249 (11.3)	3931 (11.2)	18 895 (11.2)
Other	326 (3.1)	1302 (5.3)	2159 (4.1)	1100 (4.1)	871 (4.4)	1560 (4.4)	7318 (4.3)
Unemployed	435 (4.1)	1342 (5.5)	1747 (3.3)	1112 (4.1)	1012 (5.1)	1990 (5.7)	7638 (4.5)
Unknown	37 (0.3)	179 (0.7)	373 (0.7)	221 (0.8)	131 (0.7)	244 (0.7)	1185 (0.7)
Missing	1522	2692	7280	3900	2398	3652	21 444
Parity (%)							
0	5026 (42.5)	9851 (37.6)	26 118 (44.4)	12 240 (43.1)	8671 (39.8)	15 495 (42.3)	77 401 (42.2)
1	4261 (36.0)	10 078 (38.4)	22 645 (38.5)	10 540 (37.1)	8207 (37.7)	13 821 (37.8)	69 552 (37.9)

Table 1. Continued

	Region						Total
	North	Central	Capital	West	South East	South	
2	1700 (14.4)	3865 (14.7)	7334 (12.5)	3734 (13.1)	3327 (15.3)	5081 (13.9)	25 041 (13.6)
3	511 (4.3)	1377 (5.3)	1813 (3.1)	1066 (3.8)	930 (4.3)	1396 (3.8)	7093 (3.9)
4	194 (1.6)	517 (2.0)	514 (0.9)	431 (1.5)	353 (1.6)	488 (1.3)	2497 (1.4)
≥5	142 (1.2)	539 (2.1)	337 (0.6)	389 (1.4)	310 (1.4)	330 (0.9)	2047 (1.1)
Missing	269	946	671	2518	473	2250	7127
BMI (kg/m <sup>2</sup> )							
<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)	13 342 (52.2)	37 066 (64.9)	16 491 (59.5)	12 048 (55.9)	20 729 (58.1)	106 077 (59.2)
25 ≤ 30 (%)	3008 (26.4)	7039 (27.5)	12 728 (22.3)	6933 (25.0)	5792 (26.9)	9361 (26.2)	44 861 (25.0)
30 ≤ 35 (%)	1158 (10.1)	3097 (12.1)	4194 (7.3)	2520 (9.1)	2257 (10.5)	3297 (9.2)	16 523 (9.2)
35 ≤ 40 (%)	401 (3.5)	1028 (4.0)	1130 (2.0)	795 (2.9)	725 (3.4)	1000 (2.8)	5079 (2.8)
≥40 (%)	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	11 653
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 (25 <sup>th</sup> –75 <sup>th</sup> )	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 (6.0)	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 (5.5)	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)
Snuff use at registration at antenatal care (%)							
Yes	541 (4.5)	387 (1.8)	578 (1.0)	271 (0.9)	211 (1.2)	202 (0.5)	2190 (1.2)
In vitro fertilization (%)							
Yes	312 (2.9)	690 (2.7)	3573 (6.1)	947 (3.8)	547 (2.6)	778 (2.6)	6847 (4.0)
Self-reported health prior to pregnancy (%)							
Very good	3094 (29.3)	5966 (24.4)	16 347 (31.3)	6617 (24.6)	5958 (30.0)	11 164 (31.8)	49 146 (29.1)
Good	5536 (52.4)	13 172 (53.8)	26 066 (50.0)	14 046 (52.2)	10 151 (51.1)	19 009 (54.1)	87 980 (52.0)
Neither good or bad	738 (7.0)	1850 (7.6)	3229 (6.2)	1738 (6.5)	1249 (6.3)	2100 (6.0)	10 904 (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)	16 939 (10.0)
Missing	1539	2699	7282	3995	2406	3703	21 624
Self-reported health during pregnancy (%)							

Table 1. Continued

	Region						Total
	North	Central	Capital	West	South East	South	
Very good	1452 (19.2)	3091 (16.9)	6252 (20.3)	3626 (18.2)	3377 (20.1)	6457 (21.6)	24 255 (19.7)
Good	3839 (50.7)	9505 (52.1)	15 633 (50.8)	10 136 (50.9)	8556 (50.8)	15 580 (52.2)	63 249 (51.3)
Neither good or bad	877 (11.6)	2249 (12.3)	3241 (10.5)	2425 (12.2)	1973 (11.7)	3582 (12.0)	14 347 (11.6)
Poor	489 (6.5)	1153 (6.3)	1727 (5.6)	1194 (6.0)	995 (5.9)	1853 (6.2)	7411 (6.0)
Very poor	115 (1.5)	274 (1.5)	412 (1.3)	341 (1.7)	245 (1.5)	495 (1.7)	1882 (1.5)
Unknown	804 (10.6)	1975 (10.8)	3516 (11.4)	2179 (10.9)	1692 (10.0)	1873 (6.3)	12 039 (9.8)
No follow-up visit/missing	4527	8926	28 651	11 017	5433	9021	67 575
Self-reported health after pregnancy (%)							
Very good	2430 (32.1)	5388 (29.5)	9732 (31.6)	6035 (30.3)	5642 (33.5)	10 797 (36.2)	40 024 (32.5)
Good	3793 (50.1)	9505 (52.1)	15 464 (50.2)	10 048 (50.5)	8316 (49.4)	15 087 (50.6)	62 213 (50.5)
Neither good or bad	425 (5.6)	1062 (5.8)	1643 (5.3)	1292 (6.5)	869 (5.2)	1631 (5.5)	6922 (5.6)
Poor	117 (1.5)	338 (1.9)	491 (1.6)	424 (2.1)	296 (1.8)	504 (1.7)	2170 (1.8)
Very poor	26 (0.3)	94 (0.5)	140 (0.5)	108 (0.5)	95 (0.6)	155 (0.5)	618 (0.5)
Unknown	786 (10.4)	1859 (10.2)	3311 (10.8)	1993 (10.0)	1621 (9.6)	1666 (5.6)	11 236 (9.1)
No follow-up visit/missing	4526	8927	28 651	11 018	5432	9021	67 575
Counseling due to fear of childbirth (%)							
Yes	759 (7.5)	1603 (6.6)	4446 (9.8)	1672 (6.9)	1449 (7.5)	2334 (6.9)	12 263 (7.8)
No	9305 (91.6)	22 434 (92.5)	40 203 (89.0)	22 402 (92.4)	17 821 (92.2)	31 225 (92.0)	143 390 (91.3)
Unknown	93 (0.9)	214 (0.9)	537 (1.2)	169 (0.7)	50 (0.3)	369 (1.1)	1432 (0.9)
Missing	1946	2922	14 246	6675	2951	4933	33 673
First visit antenatal care, gestational week							
Mean (SD)	9.9 (4.5)	9.8 (5.3)	9.7 (4.6)	8.8 (4.6)	9.5 (4.6)	9.4 (5.0)	9.5 (4.8)
Median (25 <sup>th</sup> –75 <sup>th</sup> )	9.0 (7.0–11.0)	9.0 (7.0–11.0)	9.0 (7.0–10.0)	8.0 (6.0–10.0)	9.0 (7.0–10.0)	8.0 (7.0–10.0)	9.0 (7.0–10.0)
Missing (%)	1554 (12.8)	2773 (10.2)	7416 (12.5)	4007 (13.0)	2514 (11.3)	3748 (9.6)	22 012 (11.5)
Screening for intimate partner violence (%)							
Yes	8624 (85.0)	17 595 (72.6)	34 061 (75.4)	17 631 (72.7)	17 488 (90.5)	24 646 (72.6)	120 045 (76.4)
No	651 (6.4)	4514 (18.6)	8054 (17.8)	5280 (21.8)	1157 (6.0)	6130 (18.1)	25 786 (16.4)
Unknown	874 (8.6)	2137 (8.8)	3077 (6.8)	1334 (5.5)	674 (3.5)	3149 (9.3)	11 245 (7.2)
Missing	1954	2927	14 240	6673	2952	4936	33 682
Gestational diabetes (%)							
Yes	120 (1.2)	471 (1.9)	445 (1.0)	232 (1.0)	301 (1.6)	905 (2.7)	2474 (1.6)
No	9973 (98.2)	23 645 (97.5)	44 394 (98.2)	23 925 (98.7)	18 996 (98.3)	32 825 (96.8)	153 758 (97.9)
Unknown	63 (0.6)	137 (0.6)	350 (0.8)	88 (0.4)	22 (0.1)	197 (0.6)	857 (0.5)
Missing	1947	2920	14 243	6673	2952	4934	33 669
Treatment for psychiatric disorder during pregnancy (%)							
Yes	1053 (9.0)	3661 (14.1)	6109 (10.5)	1920 (6.5)	2808 (12.9)	4423 (11.9)	19 974 (10.8)
No	10 593 (91.0)	22 382 (85.9)	52 240 (89.5)	27 684 (93.5)	18 943 (87.1)	32 762 (88.1)	164 604 (89.2)
Missing	457	1130	1083	1314	520	1676	6180
Follow-up visit after childbirth at antenatal care (%)							

Table 1. Continued

	Region							Total
	North	Central	Capital	West	South East	South		
Yes	7536 (62.3)	18 214 (67.0)	30 711 (51.7)	19 860 (64.2)	16 777 (75.3)	29 754 (76.6)	122 852 (64.4)	
No	4567 (37.7)	8959 (33.0)	28 721 (48.3)	11 058 (35.8)	5494 (24.7)	9107 (23.4)	67 906 (35.6)	
Breastfeeding at discharge from delivery hospital (%)								
Yes, completely	5053 (88.1)	20 253 (86.1)	42 237 (76.1)	8463 (76.1)	16 822 (85.2)	27 875 (81.3)	120 703 (80.5)	
Yes, partly	493 (8.6)	2428 (10.3)	11 609 (20.9)	2011 (18.1)	2024 (10.3)	4661 (13.6)	23 226 (15.5)	
No	191 (3.3)	840 (3.6)	1685 (3.0)	648 (5.8)	897 (4.5)	1738 (5.1)	5999 (4.0)	
Missing	6366	3652	3901	19 796	2528	4587	40 830	

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.

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  $\pm 10\%$  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

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

<i>n</i> = 154 154	Nuchal translucency	%	Combined FTS	%	Test positive %
Trisomy 21, <i>n</i> = 653	471/653	72	579/653	89	4.5
Trisomy 18, <i>n</i> = 222	119/179	66	155/279	87	0.6
Trisomy 13, <i>n</i> = 81	51/72	71	57/72	79	
Triploidy, <i>n</i> = 35	24/35	69	35/35	100	
Turner syndrome, <i>n</i> = 46	39/46	85	42/46	91	
Total, <i>n</i> = 985	704/985	71	868/985	88	5.1

**Table 3.** Detection rates of chromosomal anomalies and positive test ratios after combined first trimester screening (FTS), 2015.

<i>n</i> = 34 796	Nuchal translucency	%	Combined FTS	%	Test positive %
Trisomy 21, <i>n</i> = 131	101/131	77	121/131	92	3.8
Trisomy 18, <i>n</i> = 43	30/43	70	36/43	84	0.5
Trisomy 13, <i>n</i> = 9	6/9	67	6/9	67	
Triploidy, <i>n</i> = 10	3/10	30	10/10	100	
Turner syndrome, <i>n</i> = 16	13/16	81	14/16	88	
Total, <i>n</i> = 209	153/209	73	187/209	89	4.3

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/m<sup>2</sup>. 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.

Detection rates of chromosomal anomalies and positive test ratios following combined FTS for the period 2006–2014 are presented in Table 2 and for the year 2015 in Table 3. A total of 154 154 fetuses were screened during 2006–2014 and 34 796 in 2015. In 2006–2014 period, 579

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



**Table 4.** Delivery outcomes for births in 2014–2015 by Swedish region.

Measure	Region (%)						Total (%)
	North	Central	Capital	West	South East	South	
<i>n</i>	12 103	27 173	59 432	30 918	22 271	38 861	190 758
Mode of delivery							
Cesarean section	1883 (15.6)	4496 (16.5)	12 713 (21.4)	4801 (15.5)	3032 (13.6)	6075 (15.6)	33 000 (17.3)
Forceps	8 (0.1)	3 (0.0)	24 (0.0)	17 (0.1)	11 (0.0)	89 (0.2)	152 (0.1)
Vacuum extraction	759 (6.3)	1605 (5.9)	3830 (6.4)	1425 (4.6)	1182 (5.3)	2331 (6.0)	11 132 (5.8)
Vaginal, non-instrumental	9453 (78.1)	21 069 (77.5)	42 865 (72.1)	24 675 (79.8)	18 046 (81.0)	30 366 (78.1)	146 474 (76.8)
Gestational age							
<32	146 (1.2)	222 (0.8)	563 (0.9)	359 (1.2)	218 (1.0)	379 (1.0)	1887 (1.0)
32–36	561 (4.6)	1384 (5.1)	2657 (4.5)	1446 (4.7)	1029 (4.6)	1943 (5.0)	9020 (4.7)
≥37	11 395 (94.2)	25 567 (94.1)	56 212 (94.6)	29 104 (94.1)	21 021 (94.4)	36 535 (94.0)	179 834 (94.3)
Induction of labor							
Yes	2039 (16.8)	4440 (16.3)	11 541 (19.4)	4603 (14.9)	3770 (16.9)	6485 (16.7)	32 878 (17.2)
Of which ended in cesarean section	357 (17.5)	799 (18.0)	2203 (19.1)	840 (18.2)	531 (14.1)	1146 (17.7)	5876 (17.9)
No	10 064 (83.2)	22 733 (83.7)	47 891 (80.6)	26 315 (85.1)	18 501 (83.1)	32 376 (83.3)	157 880 (82.8)
5-min Apgar scores, term pregnancies							
0–3	43 (0.4)	153 (0.6)	327 (0.6)	130 (0.4)	85 (0.4)	200 (0.5)	938 (0.5)
4–6	174 (1.5)	384 (1.4)	475 (0.8)	304 (1.0)	237 (1.1)	364 (0.9)	1938 (1.0)
7–10	11 777 (98.2)	26 462 (98.0)	58 442 (98.6)	30 225 (98.6)	21 773 (98.5)	38 146 (98.5)	186 825 (98.5)
Missing	109	174	188	259	176	151	1057
Postpartum hemorrhage >1000 mL							
Cesarean delivery	225 (11.9)	692 (15.3)	1692 (13.3)	674 (14.0)	336 (11.1)	689 (11.3)	4308 (13.0)
Vaginal delivery	487 (4.8)	1148 (5.1)	3486 (7.5)	1945 (7.5)	880 (4.6)	1564 (4.8)	9510 (6.0)
Obstetric anal sphincter injury							
Non-instrumental delivery	239 (2.5)	466 (2.2)	1526 (3.6)	534 (2.2)	439 (2.4)	734 (2.4)	3938 (2.7)
Instrumental delivery	85 (11.0)	170 (10.5)	551 (14.2)	134 (9.2)	138 (11.5)	265 (10.9)	1343 (11.8)
Stillbirth	43 (0.4)	114 (0.4)	210 (0.3)	131 (0.4)	120 (0.5)	131 (0.3)	749 (0.4)
Cord pH sampling							
Overall	10 938 (90.4)	25 007 (92.0)	43 414 (73.0)	26 183 (84.7)	21 325 (95.8)	31 410 (80.8)	158 277 (83.0)
Proportion for Apgar 5-min <7	175 (80.6)	432 (80.4)	521 (65.0)	329 (75.8)	283 (87.9)	342 (60.6)	2082 (72.4)
Self-reported delivery experience <sup>a</sup>							
<i>N</i>	6911	15 506	29 776	17 031	–	19 700	88 924
1–3	107 (4.0)	253 (4.5)	744 (3.2)	88 (4.7)	–	179 (3.0)	1371 (3.5)
4–6	398 (15.0)	869 (15.6)	2498 (10.8)	339 (18.2)	–	751 (12.5)	4855 (12.4)
7–10	2151 (81.0)	4463 (79.9)	19 834 (86.0)	1433 (77.0)	–	5061 (84.5)	32 942 (84.1)
Missing	4255	9921	6700	15 171	–	13 709	49 756

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.

<sup>a</sup>Deliveries during 2015 and not including Blekinge, Jönköping, Kalmar or Östergötland.

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

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 fulfil 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 ( $\geq 95\%$ ) 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.

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## 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.