


Swedish Child Health Services Register: a quality register for child health services and children's well-being

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ABSTRACT

Background Swedish child health services (CHS) is a free-of-charge healthcare system that reaches almost all children under the age of 6. The aim for the CHS is to improve children's physical, psychological and social health by promoting health and development, preventing illness and detecting emerging problems early in the child's life. The services are defined in a national programme divided into three parts: universal interventions, targeted interventions and indicated interventions.

The Swedish Child Health Services Register (BHVQ) is a national Quality Register developed in 2013. The register extracts data from the child's health record and automatically presents current data in real time. At present, the register includes 21 variables.

Aim We aim to describe data available in the BHVQ and the completeness of data in BHVQ across variables.

Methods Child-specific data were exported from the register, and data for children born in the regions were retrieved from Statistics Sweden to calculate coverage.

Results The register includes over 110 000 children born between 2011 and 2022 from 221 child healthcare centres in eight of Sweden's 21 regions. In seven of the eight regions, 100% of centres report data. The completeness of data differs between participating regions and birth cohorts. The average coverage for children born in 2021 is 71%.

Conclusions The BHVQ is a valuable resource for evaluating Child Health Services nationally, with high coverage for the youngest children. As a result of continuous improvement of the services, the possibility to follow the development of children's health in Sweden is possible through the register. When fully expanded, the register will be a natural and essential part of developing preventive services, improving healthcare for children below 6 years of age and a tool for developing evidence-based child health interventions.

INTRODUCTION

Child health services (CHS) in Sweden are free-of-charge and a nationwide healthcare system for children living in Sweden under the age of 6. This covers approximately 710 000 children. The CHS has high credibility in

WHAT IS KNOWN ABOUT THE SUBJECT?

- ⇒ Swedish child health service aim is to improve children's physical, psychological and social health by promoting health and development.
- ⇒ The services are defined in a national programme divided into three parts: universal interventions, targeted interventions and indicated interventions.
- ⇒ Almost all children in Sweden attend regular visits in the child health services.

WHAT THIS STUDY ADDS?

- ⇒ The Swedish Child Health Services Register has a high coverage among the youngest children in the eight participating regions.
- ⇒ The register contains data on over 110 000 children; in seven of the eight regions, 100% of centres report data.
- ⇒ The data in the child health services records are automatically exported to the Swedish Child Health Services Register.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

- ⇒ The Swedish Child Health Services Register is a valuable resource for evaluating methods in used in the Child Health Services.
- ⇒ Data in the register can be a valuable resource for research regarding children's health.
- ⇒ By using personal identification number in the register, it is possible to link data between registries.

the Swedish community, and almost all children attend at least one regular visit to CHS.¹ The CHS aims to improve children's physical, psychological and social health by promoting health and development, preventing illness and detecting emerging problems in the child's environment. In the CHS, children and families receive preventive healthcare such as vaccinations, parental support and healthy lifestyle promotion. Regular check-ups regarding psychomotor and language development, growth monitoring and vision and hearing screenings are



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carried out. The services are defined in a national CHS programme divided into three parts: universal interventions, targeted interventions and indicated interventions.² Foremost, the programme is delivered by a registered specialist nurse in primary or paediatric care. The universal part consists of 15–16 health visits, of which 11–12 visits are during the child's first 12 months. Four team visits with a nurse and a physician, according to the programme, are also included. All the interventions in the programme are based on principles of proportionate universalism. They should be adjusted to the needs of every family^{3 4}; thus, the programme can lead to more than 16 visits. The programme is based on the United Nations' Convention on the Rights of the Child.⁵ The CHS have a unique opportunity to intervene early when staff are concerned about a child's well-being.⁶

Child health records and regional child health units

Electronic health records (EHR) have been implemented in the CHS in 20 out of 21 Swedish regions, and the records are well structured, with some regional differences.

In most regions, the staff receive supervision, training, consultation and support in implementing new methods and improvement work from a regional CHS unit, most often consisting of a nurse, a physician and a psychologist. The Swedish CHS has a long tradition of data-driven quality improvement and evaluation processes in which the regional CHS units have a major role. Traditionally, the evaluation of the CHS has been performed through regional annual reports of statistics shared with the CHS providers in dialogue meetings. The statistics have been manually reported by each clinic or extracted from the respective data journal system—often a combination of these methods, thereby these reports have already been outdated when presented due to time lag.

The Swedish Child Health Services Register

Based on the need for a national structure for collection of statistical data for quality improvement, the Swedish Child Health Services Register (BHVQ) was the result of an interprofessional national effort to define quality indicators for preventive child healthcare. In 2013, financial support was granted by the Swedish Association of Local Authorities and Regions and a formal board was formed.

BHVQ aims to improve the quality of the care offered within CHS and, as a result, follow the health status of children. Most measurements chosen are healthcare indicators and determinants for children's long-term health. BHVQ makes it possible to measure health access and outcomes from the CHS programme in both short-term and long-term time horizons.⁷ In the Swedish national system for knowledge-driven management,⁸ BHVQ's role is to evaluate and deliver data to enable monitoring the national programme nationwide. This facilitates the national system for knowledge-driven management to suggest adding or subtracting indicators in the CHS and BHVQ.

Furthermore, BHVQ is today managed by a register holder and a board of members from different regions in Sweden, including all professions participating in the CHS. Half of the board members have a relevant PhD, and all have a long experience working in the CHS.

Regulations and prospects

Sweden has a long history of using and combining data from different registries for scientific purposes.⁹ It is considered a part of the national structure of research and healthcare.¹⁰ The personal identification number (PIN) is recommended to be used as a base for all registries in Sweden,¹¹ which allows data to be combined with other registers and thereafter pseudonymised. The use of PINs and personal data is controlled by regulations regarding the General Data Protection Regulation and Swedish national laws.¹² Data usage inside national quality registries is regulated in the Swedish patient data act.¹³ For national quality registries, the legislation makes it possible to collect data about patients and patient care with the obligation to inform patients of data collection for a register. The patient can request not to be included in the register and erase data.¹³

Aim

We aim to describe:

1. Data available in the BHVQ.
2. Completeness of data in BHVQ across variables.

METHODS

For this study, child-specific data were exported from the register's internal Microsoft Power BI Self-Service portal. Microsoft Power BI calculations were conducted with data extraction from the BHVQ database and analysed and summarised in Microsoft Excel (V.2022). Data for children born in each region were retrieved from Statistics Sweden.

Variables in the register

BHVQ includes 21 variables, for example, home visits, screening for maternal mental health, growth, language screening and exposure to secondhand smoking, of which most are collected continuously at the visits in the CHS. See online supplemental appendix 1 for a complete list of variables.

Home visits

Two home visits are included in the CHS programme. The first visit is conducted during the first 30 days after birth, and the second around 8 months post-partum.¹⁴ Home visits can promote childhood development, identify risk factors and improve parenting skills.¹⁵ BHVQ enables regions to follow the frequency of home visits, allowing for resource allocation. Several projects are ongoing regarding extended home visiting programmes in Sweden.^{15–17} The data structure for the home visits in the BHVQ can be used for collecting data on additional home visits.

Parental mental health problems

In BHVQ, participating in the Edinburgh Postnatal Depression Screening¹⁸ is observed for every child's mother and reported as a bivariate variable (Have/have not received Edinburgh Postnatal Depression Screening). In most regions, one visit for the non-birth-giving parent is implemented and followed in the BHVQ.

Growth

The register monitors all measures on length, height and weight in children at all visits conducted at the CHS.¹⁹ Body mass index is calculated and presented at three ages: two and a half, four and five.²⁰ Since the register follows individual data, further analysis of trajectories is possible.

Language screening

The CHS programme includes a language screening at 2.5 or 3 years of age. There are two methods available, and BHVQ provides data usage of both methods.^{21 22}

Patient-reported measurements

Patient-reported outcome measures are used in BHVQ regarding exposure to secondhand tobacco smoke and the child's breast milk intake or breast feeding, which both are strongly associated with child health outcomes.^{23–26}

Data collection and storage

The child health records, administrated by the CHS, are the data sources for the register with the child's PIN as the primary key. Data are automatically exported to the register's server via a national service-contract platform or point-to-point. As new information is added to the child's health record, the register is updated. Furthermore, the data are stored on a web platform in a Structured Query Language-Server.

To provide feedback to participating regions, centres and nurses, variables are published online in aggregated form in an interactive report with the possibility of combining data. This enables professionals and decision-makers to follow the quality and production of services in the CHS. A two-step authorisation provides access to detailed data in a specific region.

Validation of data

To study the validity of the data in the register, a comparison is made with data in the child's health record in all regions delivering data to the BHVQ, which is audited annually. All variables and their specific values are audited in a specific age category. Age categories 0–12 months, 1–2 years and 3–5 years are used. All variables and values are thereby audited within 3 years.

Ethical issues and data available for research

All caregivers who visit the CHS with their child receive information that data from the child's health record are exported to BHVQ, with the possibility to opt out at any time in accordance with current legislation.¹³

Table 1 Number of children in BHVQ and proportion of all children in Sweden according to Statistics Sweden (31 December 2021)

Birth cohort	Total amount of children in the BHVQ N	Percentage of children in Sweden in BHVQ
2011	73	0
2012	530	0
2013	1335	1
2014	3623	3
2015	4984	4
2016	6785	5
2017	14 713	12
2018	15 471	13
2019	14 906	13
2020	16 701	15
2021	17 810	16
2022	14 206	No denominator available for this birth cohort
Total	111 137	

BHVQ, The Swedish Child Health Services Register.

After approval from an ethical review board, researchers may obtain pseudonymised data from BHVQ to link to other national and quality registers. This enables following children over time or analysing a single birth cohort.

RESULTS

Population

The register aims to include children in Sweden aged 0–5 who have attended CHS and whose caregivers have not opted-out of participation. In January 2023, the register contained data from over 110 000 children born between 2011 and 2022 from participating regions (table 1).

Participating regions

Eight regions in Sweden deliver data from 221 CHS centres. Since 2017, when the region of Dalarna started to deliver data, there have been continuous data transfer projects in several other regions. Hence, the number of children with data in the BHVQ differs between birth cohorts and regions (table 2). In total, 100% of the CHS centres in seven of the eight regions deliver data to the BHVQ.

Coverage

The completeness of data is compared with data from Statistics Sweden on children born in each region to calculate the coverage (table 2). The completeness of data differs between regions and birth cohorts. The average coverage for children born in 2021 in participating

**Table 2** Coverage per region in Sweden

Region in Sweden	Start		Children living in the region N	Children in the BHVQ N (%)
	Year and month for delivering data to BHVQ	Birth cohort		
Dalarna	September 2017	2021	2816	2 840 (100)
		2020	2965	3 026 (100)
		2019	3059	2 963 (97)
		2018	3195	2 946 (92)
		2017	3279	2 824 (86)
Gotland	September 2022	2021	532	562 (100)
		2020	496	500 (100)
		2019	566	548 (97)
		2018	585	563 (96)
		2017	637	620 (97)
Gävleborg	December 2021	2021	2770	1 890 (68)
		2020	2815	760 (27)
		2019	2986	439 (15)
		2018	3276	531 (16)
		2017	3099	603 (19)
Jönköping	March 2019	2021	4054	2 514 (62)
		2020	4288	3 757 (88)
		2019	4274	4 020 (94)
		2018	4416	3 843 (87)
		2017	4341	3 147 (72)
Kronoberg	October 2022	2021	2275	1 949 (86)
		2020	2402	1 878 (78)
		2019	2412	1 821 (75)
		2018	2370	1 844 (78)
		2017	2398	1856 (77)
Stockholm	November 2022	2021	28 880	2 905 (10)
		2020	28 288	1 805 (6)
		2019	28 352	2 164 (8)
		2018	28 522	2 470 (9)
		2017	28 968	2 466 (9)
Södermanland	October 2020	2021	3113	3 035 (97)
		2020	3258	3 143 (96)
		2019	3344	2 719 (81)
		2018	3593	2 777 (77)
		2017	3739	2 870 (77)
Västernorrland	October 2022	2021	2393	2 178 (91)
		2020	2325	1 892 (81)
		2019	2531	293 (12)
		2018	2658	545 (21)
		2017	2585	383 (15)

The number of children in each region based on data from Statistics Sweden (31 December 2021) compared with the number of children in the BHVQ per birth cohort. In Stockholm, only one healthcare provider delivers data. In 2023, remaining providers expect to start delivering data. BHVQ, The Swedish Child Health Services Register.

regions is 71%. Since the children must attend the CHS to be included in the register (information obligatory), a relatively higher proportion of the youngest children are included in the register (table 2). Children in the BHVQ include those who have had at least one visit to a specific centre in the region at least once. Families have the right to choose to have their child's healthcare provided in a different region than the one in which they live. Consequently, a total regional coverage does not indicate that all children living in the region have attended a visit in that specific region.

Registry data

The registry contains data from visits in the CHS, home visits and health outcomes. Table 3 shows some of the most requested data available in the register. Both data on attended home visits, screenings and health outcomes of these can be exported from the register. Data are reported aggregated, but individual data are available for research. In online supplemental appendix 2, number of children with visits per year and specific age is reported.

DISCUSSION

BHVQ, as part of the local data-driven quality improvement in the CHS

BHVQ allows the CHS to follow and monitor the CHS programme at every clinic. It also enables an automatic collection of data and a data-driven workflow for the CHS. Through the BHVQ, regions can monitor their data continuously, avoid annual reports with outdated data and compare data nationally. Before BHVQ, annual reports were aggregated regionally with less relevant data for each clinic and could be perceived as criticism and, therefore, tended to be less of a motivation.^{27–29} It could also mean that there was a risk of receiving feedback far too late on negative trends due to outdated data for organisational changes. Using the BHVQ, deviations and variations in the service can be detected early, and relevant interventions can be implemented. The BHVQ provides data to enable data-driven continuous quality improvement within the CHS. With the ability to use the PIN for individuals included in the BHVQ, it is possible to link data to other data sources; moreover, it enables the evaluation of preventive services and their long-term effects. BHVQ can be a tool and a reference for following universal and targeted interventions in the CHS programme.

Several methods used in the CHS programme have limited evidence and are criticised.^{30–32} Using BHVQ methods can be evaluated and gain validity or be discarded from the national CHS programme. BHVQ can therefore be used to develop and evaluate future methods.

Ethical considerations

Data on healthcare utilisation and health are sensitive and must be secured. In the BHVQ, the PIN is used as

Table 3 Results of activities and measurements in the CHS that are exported to the BHVQ

Birth cohort	Received home visits	Received EPDS	Children who got breast milk at 4 months of age	Exposure to secondhand smoke at 8 months of age; mother smokes	Exposure to secondhand smoke at 8 months of age; father smokes	Language screening at 2.5–3 years of age		Obesity at 2.5–3 years of age	Underweight at 4 years of age	Overweight at 4 years of age	Obesity at 4 years of age
						Positive on language screening at 2.5–3 years of age	Negative on language screening at 2.5–3 years of age				
2011									3	13	2
2012						20	80	16	1	14	3
2013						17	83	3	1	21	5
2014				3,9	7,1	15	85	6	2	18	4
2015	55	59	72	5,2	8,5	16	84	32	2	17	3
2016	70	65	70	6,2	8,4	14	88	11	2	16	3
2017	75	70	71	3,4	6,5	12	90	26	2	18	4
2018	72	51	72	3,9	7,2	12	88	20	2	17	4
2019	78	64	71	3,6	7,5	13	87	11	2	14	3
2020	63	79	72	2,9	6,2	16	85	6	1	12	2
2021	74	76	69	2,7	5,4						
2022	79	73	71	1,6	3,7						

In percentages.
 BHVQ, The Swedish Child Health Services Register; CHS, child health services; EPDS, Edinburgh Postnatal Depression Screening.



a key; however, when data are exported for research, it must be deidentified or pseudo-anonymised. In register research, data shall be handled with discretion. If the data set contains a large amount of data, the possibility to recognise an individual is minimised. All reporting should be aggregated to avoid the possibility of identifying an individual.

Strengths and limitations

This study is based on data available in the register. Compared nationally, the coverage in the register is low, but from a regional perspective, most younger cohorts have almost complete coverage. Several regions have ongoing projects to deliver data to the BHVQ, and the coverage for every new birth cohort is increasing. Continuous improvements and data validation create opportunities for the register to increase coverage and widen its usage. The difference in coverage between regions that send data to the BHVQ depends on several factors. All guardians must be informed about the BHVQ before data are transferred to the register. During the child's first year of life, the visits to CHS are more frequent, followed by annual visits. The time delay can be a year or more if the nurse fails to inform the parents about data export to the register. Also, the regional context affects coverage; for example, when EHRs were implemented.

One limitation of this study is that data regarding the quality of CHS and children's health are not analysed. Further studies are needed to evaluate the CHS and give further recommendations regarding changes in the national CHS programme.

Limitations in the documentation and inconsistent documentation are major challenges for the register, together with several active EHR systems in Sweden. Variations in documentation between regions affect the quality of data. For example, the variable regarding exposure to secondhand smoke differs between regions, where some regions report dichotomous variables, and others only document the presence of exposure. The development of the BHVQ must, therefore, be flexible to include as much data as possible and secure a high-quality level.

CONCLUSIONS

This brief description of the data available in BHVQ shows that the BHVQ is a valuable resource for evaluating CHS at a national level. The completeness of data varies between regions and variables and is increasing as more regions deliver data.

As a result of continuous improvement of the services, the possibility to follow the development of children's health in Sweden is possible through BHVQ. When fully expanded, the register will be a natural and essential part of developing preventive services, improving healthcare for children below 6 years of age, and a tool for developing evidence-based child health interventions.

Accessing the data online allows decision-makers and healthcare workers to follow and analyse the CHS programme's outcomes easily. The ambition of the register is that the online platform facilitates resource allocation and improvements to the population's needs as a data-driven method.

The authors strongly recommend expanding and improving the BHVQ to promote children's health and develop evidence-based child healthcare.

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Variable	Description	Age of measurements
First born child	Is the child the first born child for any caregiver	0-5 years old
Home visits	Received home visits, per child. Two home visits are a part of the national program from child health care	0-5 years old
Visits at the clinics	Visits at the CHC, per child. Presented per profession the child met at the visits (nurse, physician, paediatrician and GP)	0-5 years old
Team visits at the clinics	Children who meet both a physician and a specialist nurse at the CHC	0-5 years old
Parental support in group	Children whose caregivers participated in a parental support group at the CHC. The groups are usually conducted during the child's first year.	0-5 years old
Postnatal Depression Screening	Children where the mother/birth-giving parent participated in screening for postnatal depression using the Edinburgh Postnatal Depression Scale (EPDS)	6-8 weeks
Individual conversation with the non birth giving caregiver	Children where the father/non-birth-giving parent participated in an individual conversation at the CHC regarding mental health and parenthood	3-5 months
Breastfeeding status	Breastfeeding status during the first year with measurements after 1 week, 2, 4, 6, 8 and 12 months	0-12 months
Vaccinations	Number of doses per child and vaccine in the national vaccination programme for children. This includes vaccinations against rotavirus infection, diphtheria, tetanus, pertussis, polio, Haemophilus influenzae type b, pneumococcal disease, measles, mumps, and rubella. For children "at-risk" the vaccination program also includes selective vaccination against tuberculosis, hepatitis B, influenza and invasive pneumococcal disease, for BHVQ tuberculosis and hepatitis B is included	0-5 years old. National measurement standard at 2 years
Second-hand smoking	Exposure to second hand smoke by caregivers who smokes or the occurrence of smoking in the child's home	4 weeks, 8 months and 18 months
Growth	Weight, Length/Height, Head Circumference (during the first 18 months), Gestational age at birth and biological parents length. Body mass index (BMI) is calculated at 2,5-3 years, 4 years and 5 years	0-5 years old
Language and communication screening	Completed, no need for assessment and result of screening	2,5-3 years
Audiology screening	Completed, no need for assessment and result of screening	4 years
Ophthalmic screening	Completed, no need for assessment and result of screening	4 years
Developmental assessment	Completed, no need for assessment and result of screening	4 years

Referrals	Referrals send from CHC to audiologist, paediatrician, physiotherapist, speech and language pathologist, orthoptist and psychologist per child	0-5 years old
Date of discharge from delivery ward and maternity ward	Date of discharge from delivery ward and maternity ward	0-3 months
Accidents	Indicators of pre-school children's health	12 months and 4 years
Antibiotics	Indicators of pre-school children's health	12 months and 4 years
Asthma	Indicators of pre-school children's health	12 months and 4 years
Eczema	Indicators of pre-school children's health	12 months and 4 years

Appendix 2. The total amount of children in the register with visits at a specific age

Birth Cohort	Total amount of children in the BHVQ	Children with at least one visit at age 0-3 weeks (0-18 days)	Children with at least one visit at age 0-6 weeks (0-42 days)	Children with at least one visit at age 0 weeks - 2 months and 3 weeks (0-82 days)	Children with at least one visit at 4 months of age 105-143 days	Children with at least one visit at 6 months of age (167-213 days)	Children with at least one visit at 8 months of age (227-274 days)	Children with at least one visit at 1,5 years of age (517-638 days)	Children with at least one visit at 2,5-3 years of age (853-1186 days)	Children with at least one visit at 4 years of age (1401-1551 days)	Children with at least one visit at 5 years of age (1766-2100 days)
2011	73									62	73
2012	530		1	1	1	1	1	1	161	409	545
2013	1 335	1	1	1	1	2	1	167	982	1 096	1 304
2014	3 623	78	99	105	116	259	411	1 132	1 382	2 288	3 575
2015	4 984	827	965	1 089	1 171	1 151	1 240	1 395	2 871	4 438	4 786
2016	6 785	1 945	2 094	2 141	1 909	2 058	2 062	2 446	5 345	5 618	6 116
2017	14 713	4 619	5 093	5 274	4 833	5 277	5 554	8 103	10 886	11 585	11 819
2018	15 471	6 541	7 199	7 568	7 503	8 467	8 738	10 373	13 124	11 797	26
2019	14 906	9 543	10 104	10 428	9 737	10 225	10 297	11 715	12 449	28	
2020	16 701	12 973	13 659	13 978	12 942	13 363	13 151	13 685	4 910		
2021	17 810	14 013	15 023	15 641	13 896	14 567	14 493	6 671			
2022	14 206	12 982	13 907	14 145	8 464	6 736	4 154				
Total	111 137	63 522	68 145	70 371	60 573	62 106	60 102	55 688	52 110	37 321	28 244