

Original article | Published 26 June 2025 | doi:https://doi.org/10.57187/s.4065 Cite this as: Swiss Med Wkly. 2025;155:4065

# High data retrieval rates with SwissPedData for paediatric traumatic brain injuries in children's hospitals: a multicentre, point-prevalence study

Michael von Rhein<sup>ab</sup>, Niklaus Krayenbühl<sup>bcd</sup>, Andreas Meyer-Heim<sup>be</sup>, Sergio Manzano<sup>f</sup>, Gianluca Gualco<sup>g</sup>, Renato Gualtieri<sup>h</sup>, Fabrizio Romano<sup>i</sup>, Alexander Mack<sup>j</sup>, Larissa Hauser-Angst<sup>b</sup>, Michelle Seiler<sup>bk</sup>, on behalf of the SwissPedNet consortium<sup>l</sup>

- <sup>a</sup> Child Development Centre, University Children's Hospital, Zurich, Switzerland
- <sup>b</sup> Children's Research Centre, University Children's Hospital Zurich, University of Zurich, Zurich, Switzerland
- <sup>c</sup> Department of Neurosurgery, Clinical Neuroscience Centre, University Hospital Zurich and University of Zurich, Zurich, Switzerland
- d Division of Paediatric Neurosurgery, University Children's Hospital, Zurich, Switzerland
- <sup>e</sup> Swiss Children's Rehab, University Children's Hospital Zurich, Zurich, Switzerland
- Paediatric Emergency Department, Geneva University Hospitals, University of Geneva, Geneva, Switzerland
- <sup>9</sup> Paediatric Emergency Department, Clinics of paediatrics, Institute of Paediatrics of Southern Switzerland, EOC, Bellinzona, Switzerland
- h Paediatric Platform for Clinical Research, Department of Paediatrics, Gynaecology and Obstetrics, Faculty of Medicine, University of Geneva, Geneva, Switzerland
- Division of Paediatric Emergency Medicine, Department of Paediatrics, Inselspital, Bern University Hospital, University of Bern, Bern, Switzerland
- Department of Paediatric Surgery, Children's Hospital of Eastern Switzerland, St. Gallen, Switzerland
- <sup>k</sup> Paediatric Emergency Department, University Children's Hospital Zurich, Zurich, Switzerland
- For the SwissPedNet consortium, see the Acknowledgments

# **Summary**

STUDY AIMS: SwissPedNet aims to improve the quality of multicentre research through standardised documentation of routine healthcare data. Therefore, SwissPedData was developed as a set of defined common data elements to be documented in each electronic patient file in a standardised format. This study evaluates the preparedness of the ten SwissPedNet hospitals for SwissPedData before its nationwide implementation, focusing on: (a) whether the defined common data elements are effectively documented and can be retrieved for children presenting with traumatic brain injuries to paediatric emergency departments, and (b) analysis of the content of these common data elements to assess how children with traumatic brain injuries are treated in paediatric emergency departments across Switzerland.

METHODS: This multicentre point-prevalence study, conducted in June 2023, included all children up to 16 years presenting with traumatic brain injuries to ten SwissPed-Net paediatric emergency departments over one calendar week. To assess the documentation of common data elements, a questionnaire was developed, consisting of 21 common data elements defined by SwissPedData, covering patient demographics, accident details, symptoms, paediatric emergency department course, and if applicable, inpatient course. Each hub retrospectively collected data from the electronic health records of all traumatic brain injury patients during the specified week. The primary objective was to assess the rate of successful data retrieval, defined as the presence of documented information for specific common data elements. Data were classified as missing if no information regarding a specific common data element was found in the electronic health

record. The retrieval rate of each common data element was evaluated, and the average time investment per patient was recorded to estimate the associated workload. The secondary objectives focused on the content of the compiled common data element information, assessing causes and symptoms of traumatic brain injuries and injury severity and comparing management procedures for traumatic brain injury patients across Switzerland. Logistic regression was used to assess associations between specific patient characteristics (e.g. symptoms), the probability of having computed tomography (CT) scans in paediatric emergency departments, and the rate of hospitalisations

RESULTS: During the study period, a total of 349 children with traumatic brain injury were treated; the median age was 4.0 years (interguartile range [IQR] 2.0-7.5 years). Data retrieval rates exceeded 90% for each common data element; specifically, common data elements with numeric information were extracted in 98.3% to 100% of cases, while those with standardised options or free-text entries had a retrieval rate of 91.7% to 100%. However, data on written discharge information were available for only 51.2% of outpatients and 53.3% of inpatients, with significant variability among hospitals. Data collection efforts varied among the ten participating hubs, with an average time investment per patient ranging from 0.5 to 2 hours and limited involvement of information technology (IT) departments. The prevalence of traumatic brain injury patients at the paediatric emergency departments was 6% (range: 3% to 11.5%), with most traumatic brain injuries occurring at home (48%) or on playgrounds (18.9%). The primary trauma mechanism was a fall (56.5%), usually from a height of less than 1 metre. Most patients (99.1%) had a normal Glasgow Coma Scale (GCS). CT scans

PD Dr. med. Michelle Seiler Paediatric Emergency Department University Children's Hospital Zurich Lenggstrasse 30 CH-8008 Zurich michelle.seiler[at] kispi.uzh.ch

were performed in ten cases in the paediatric emergency departments, revealing pathologies in four cases, and resulting in neurosurgical intervention in one case. Factors associated with undergoing a CT scan or being hospitalised included lower triage category numbers and loss of consciousness.

CONCLUSIONS: Common data elements are conscientiously documented within clinical information systems for patients with traumatic brain injuries in paediatric emergency departments, but data extraction requires considerable time and effort, underscoring the need for additional technical support. Although traumatic brain injuries are a common reason for paediatric emergency department visits, they are generally mild in severity. Although Switzerland has no national guidelines for treating children with traumatic brain injuries, management practices, particularly the low rate of CT scans in children with traumatic brain injury and normal GCS, appear to be fairly consistent across hospitals.

# Introduction

Substantial volumes of patient data are generated on a daily basis in routine healthcare. Unfortunately, a significant portion of this data remains inaccessible for research purposes due to non-standardisation, lack of structure, lack of accessible interfaces, and incompleteness [1, 2]. Consequently, evidence-based improvement in paediatric health care lags behind expectations [1-3]. To enhance paediatric research potential without causing additional workload for clinical staff, a standardised data documentation system for routine data, called SwissPedData, was scheduled to be implemented across all Swiss paediatric hospitals in 2024 [3]. SwissPedData is an initiative of SwissPedNet, the clinical research network of ten Swiss children's hospitals. The project's goal is to standardise the collection of healthrelated routine data in paediatric hospitals throughout Switzerland, with the aim of establishing a national electronic health record dataset for all Swiss paediatric hospitals. A set of standardised paediatric common data elements, which must be documented as a standard practice, was developed and approved through a multi-stage consensus-finding process in 2021 [3] to facilitate accessibility for research, especially multicentre research [1].

These common data elements are categorised into two main groups, those concerning general paediatric aspects and those specific to various subspecialties, comprising over 330 common data elements [3, 4]. Since paediatric emergency medicine was not included initially in this process, experts from major Swiss paediatric emergency departments defined an additional set of 28 common data elements, analogous to the suggested minimal datasets put forth by the international paediatric emergency care applied research network (PECARN) [4].

Although common data elements for various diseases have been previously implemented in other countries, prior studies predominantly focused on the process of achieving consensus for these common data elements rather than assessing their impact on data accessibility for research [5–7]. This study addresses this gap by evaluating the implementation and retrievability of defined common data elements within Swiss children's hospitals, specifically for

children presenting with traumatic brain injuries to paediatric emergency departments.

The rationale for investigating patients with traumatic brain injuries is that they represent a significant cause of paediatric emergency presentations [8] that require structured documentation of key clinical variables, including symptoms, imaging, and management decisions. Additionally, assessing traumatic brain injury cases permits the evaluation of both structured (e.g. triage category) and unstructured (e.g. symptoms, mechanism of injury) data retrieval. The absence of national guidelines for diagnostics and treatment recommendations in Switzerland raises questions about whether traumatic brain injury management follows the same standards across Swiss children's hospitals.

Our primary aim was to assess the availability and retrievability of defined common data elements for children presenting with traumatic brain injuries to paediatric emergency departments and to evaluate the workload related to data retrieval shortly before the definitive implementation of SwissPedData. Additionally, we aimed to analyse the content of these common data elements to assess how children with traumatic brain injuries are managed in paediatric emergency departments across Switzerland.

# Methods

In June 2023, we conducted a multicentre point-prevalence study according to the specifications of SwissPedNet, including all children with traumatic brain injury presenting to paediatric emergency departments of the participating centres. All ten participating centres are members of SwissPedNet and include the University children's hospitals of Basel, Bern, Zurich, Geneva, and Lausanne, as well as the children's hospitals in Aarau, Fribourg, central Switzerland (KidZ), eastern Switzerland (St. Gallen), and Ticino.

Each SwissPedNet hospital has a dedicated research department responsible for conducting studies in compliance with the Human Research Act and its ordinances [9]. Although each hub is closely linked to the corresponding clinical trial units, there is no unified data architecture, and data collection is conducted independently at each hub. SwissPedNet has implemented a quality management system (QMS) for all clinical paediatric hubs. This QMS is based on the QMS of the clinical trial units and additionally incorporates the StaR papers to enhance quality and ethics in paediatric research [10].

After clarification with the responsible Ethics Committee in Zurich, this study was classified as a quality improvement initiative, which does not fall within the scope of the Human Research Act. Due to its focus on assessing readiness for implementing SwissPedData, no formal study protocol was prepared, and registration was not required. The Ethics Committee of Zurich, followed by the research ethics committees in Basel/ Central Switzerland, Bern, St. Gallen, Vaud, Geneva, and Ticino, issued a declaration of non-applicability (BASEC Nr. Req-2022-01210).

Each participating centre designated a specific calendar week in June for data collection, choosing among options from calendar weeks 23 to 26. The inclusion criteria were patients aged 0 to 16 years diagnosed with traumatic brain injury who presented at the paediatric emergency depart-

ments of the participating hospitals during the designated week. Exclusion criteria were direct admission to the intensive care unit or the ward without treatment in the paediatric emergency department. Each hub retrospectively collected data from the electronic health record either by generating a computed screening list for patients diagnosed with traumatic brain injury, or by manually selecting all eligible patients treated in the paediatric emergency department by checking each patient's diagnosis during the designated week. Traumatic brain injury was defined as an external force to the head with alteration in brain functions such as loss of consciousness, amnesia, any alteration in mental state, any neurologic deficits, or other evidence of brain pathology [11]. All included hospitals work with electronic patient information systems and prioritise patient care using the Australasian Triage Scale or Canadian Triage and Acuity Scale, consisting of five categories from 1 (immediately, life-threatening) to 5 (less urgent) [12, 13]. Urgent triage scales were defined as triage scales 1 to 3.

The primary objective of this study was to determine the success rate of data retrieval for SwissPedData, assessing whether routine data, specified as common data elements, were actually documented in patients' electronic health records and could be effectively retrieved. Lack of information about specific common data elements in the electronic health record was considered as missing data. We analysed patients with traumatic brain injury to evaluate common data element documentation. A questionnaire was created with variables relevant for traumatic brain injury research, such as patient demographics, accident details, symptoms, course in the paediatric emergency department, and, if applicable, course on the ward [14, 15]. These variables were selected based on a literature review of paediatric traumatic brain injury management and then compared to the common data elements defined for SwissPed-Data (table 1). The questionnaire consisted of 23 variables, 21 of which matched the SwissPedData common data elements, 19 from the general paediatrics module and 2 from the paediatric emergency medicine subspecialty. Our questionnaire contained two additional variables not included in the minimal dataset: whether families were provided with written discharge information and the Glasgow Outcome Scale Extended at hospital discharge; this is a wellknown instrument to assess eight different outcomes following a traumatic brain injury, from 8 (fully returned to normal life) to 1 (dead) [16]. SwissPedData not only defined the common data elements' content but also specified their recording format in the electronic health record: numeric data, standardised options, or free text. The format has not yet been defined for certain common data elements. In our questionnaire, response options included eight freetext common data elements, six with standardised options, five with numeric data, and two with undefined formats (radiological examination, neurosurgical intervention).

To assess the workload related to data retrieval, study coordinators from all hubs were asked to complete a questionnaire provided by SwissPedNet. The questionnaire included questions about the average time invested in data retrieval per patient and whether IT support was received. Data extraction options for common data elements were either automatic extraction from the hospitals' electronic health records with IT support or manual extraction of all necessary information. The questionnaire focused on the overall average time required rather than the time for specific parameters.

The secondary objectives addressed the medical topic of traumatic brain injury in Swiss children by analysing the content of the collected common data elements, relying on the data documented in the patients' electronic health records. This included the documented reasons for the traumatic brain injury, the symptoms experienced by patients, the severity of the injury as assessed by the Glasgow Coma Scale (GCS), the triage scale upon entrance to the paediatric emergency department, the radiological examinations performed, and whether surgery was required. The prevalence of children with traumatic brain injury treated at paediatric emergency departments was calculated at each hub by dividing the number of patients treated for traumatic brain injury at the paediatric emergency department by the total number of patients treated at the paediatric emergency department during the same week.

Additionally, we compared management procedures across Switzerland, examining the rate of CT scans performed in paediatric emergency departments, the rate of hospitalisations, and whether written hospital discharge information was provided to parents.

## Data management and statistical analysis

Dedicated study personnel at each hub anonymised all data and manually entered it into REDCap (Research Electronic Data Capture) hosted at University Children's Hospital Zurich [17, 18]. Statistical analyses were performed using IBM® SPSS® Statistics 27 (IBM, Armonk, NY). Basic descriptive statistics and frequencies were used to describe categorical variables, and means with standard deviations (SDs) were used for normally distributed data and medians with interquartile range (IQR) for skewed data. Differences between groups were analysed using a Fisher exact test for categorical data and the non-parametric Mann-Whitney U-Test for non-normally distributed continuous data. Logistic regression analysis was used to determine the association between selected predictors (age, GCS score, triage category, loss of consciousness, vomiting, amnesia, seizure, headache, mental alteration) and the likelihood of CT scans or hospitalisations among children with traumatic brain injury. These covariates were selected based on clinical relevance and prior literature on paediatric traumatic brain injury management. Both unadjusted and adjusted odds ratios (ORs) with 95% confidence intervals (CI) were calculated for each predictor. For continuous variables, the ORs represent the change per one-unit increase (e.g. per onemonth increase in age).

# Results

During the one-week study period a total of 349 children with traumatic brain injury were treated; girls comprised 141 (40.4%). Their median age was 4.0 years (IQR 2.0–7.5 years) with a range from 0 month to 16 years. While the median age of patients was similar across all ten hubs, the number of traumatic brain injury patients varied between 11 and 96 per hub (table 2).

Table 1:

Questionnaire to evaluate data retrieval in traumatic brain injury patients, utilising paediatric common data elements, defined for general paediatrics and paediatric emergency medicine. The retrieval rate is defined by documentation of this information in the electronic health records of traumatic brain injury patients.

Variable		Common data element (format)	Numerator	Denominator	Retrieva rate (%)
Patient info	ormation				
Age in mont	ths	General paediatrics (numeric data)	349	349	100%
Sex		General paediatrics (stan- dardised option)	349	349	100%
Underlying of	disease: known thrombocytopenia, anticoagulation medication / coagulation disorder	Paediatric emergency medicine (free text)	349	349	100%
Accident de	etails				
Where (hom	ne, playground, school, during sports, traffic accident, other)	General paediatrics (free text)	344	349	98.6%
Mechanism	(fall, impact against head, sports accident, traffic accident)	General paediatrics (free	347	349	99.4%
	If fall, height (<1 metre, 1–2 metres, 3–4 metres, >4 metres)	text)	196	196	100%
	If sports accident, specify (martial art, soccer, trampoline, gymnastics, other)		36	36	100%
	If traffic accident, specify (as pedestrian, riding bike, scooter, skateboard, other)		42	42	100%
	If traffic accident, helmet worn		42	42	100%
Isolated trau	umatic brain injury	General paediatrics (free text)	349	349	100%
Symptoms	prior to hospital entrance	· ·			
	at match: none, loss of consciousness (how long), nausea, vomiting (how often), vertigo, disorientation, mental or behavioural alteration, amnesia, seizure, others	General paediatrics (free text)	349	349	100%
Emergency	department				
Method of a	rrival (private, ambulance, helicopter)	Paediatric emergency medicine (standardised option)	345	349	98.9%
Time interva	al in hours since accident (<1 hour, 1–2 hours, etc., until >48 hours)	General paediatrics (free text)	340	349	97.4%
Reason for hospital visit (trauma mechanism, symptoms, bump/laceration, others)		General paediatrics (free text)	349	349	100%
Triage category (1–5)		General paediatrics (numeric data)	349	349	100%
GCS (first d	ocumented at hospital)	General paediatrics (numeric	346	349	99.1%
	Deterioration of GCS during emergency department stay	data)	331	349	94.8%
	Lowest GCS in the emergency department		331	349	94.8%
Radiologica	l examination of the head in the emergency department (X-ray, ultrasound, CT, MRI)	General paediatrics (to be	349	349	100%
	If radiological examination, result normal or abnormal	defined)	12	12	100%
	If abnormal: skull fracture, basal skull fracture, brain haemorrhage		4	4	100%
	If brain haemorrhage, epidural, subdural, parenchymatous		2	2	100%
Neurosurgio	al intervention	General paediatrics (to be defined)	349	349	100%
Managemer	nt (outpatient, inpatient)	General paediatrics (stan- dardised option)	349	349	100%
If outpa- tient	Observation in the emergency department (yes, no), if yes, how long	General paediatrics (numeric data)	289	289	100%
	Written discharge information handed out	Not part of defined common data elements	148	289	51.2%
If inpatient	Reason for hospitalisation (symptoms, trauma mechanism, patient's age, potential child abuse)	General paediatrics (free text)	60	60	100%
	Admission to intensive care unit	General paediatrics (stan- dardised option)	60	60	100%
Course on	the ward				
Radiologica	l examination of the head on the ward (X-ray, ultrasound, CT, MRI)	General paediatrics (to be	60	60	100%
	If radiological examination, result normal or abnormal	defined)	8	8	100%
	If abnormal: skull fracture, basal skull fracture, brain haemorrhage		4	4	100%
	If brain haemorrhage, epidural, subdural, parenchymatous		2	2	100%
Death (yes, no), if yes, due to head trauma		General paediatrics (stan- dardised option)	60	60	100%
Duration of	hospitalisation	General paediatrics (numeric data)	59	60	98.3%
Glasgow Ou	utcome Scale Extended (1–8)	Not part of defined common data elements	58	60	96.7%
Discharge d	lestination	General paediatrics (stan- dardised option)	55	60	91.7%

# Primary objectives

The retrieval rates for all defined common data elements in the fields of general paediatrics and paediatric emergency medicine were over 90% for each one. Specifically, data retrieval rates were 98.3% to 100% for variables documented with numeric values, including patient's age, triage category, GCS score at admission to the paediatric emergency department, and duration of hospital stay. However, data related to changes over time, such as GCS scores during the emergency department stay, were missing in 18 cases, resulting in a retrieval rate of 94.8% (table 1).

Information obtained from standardised answer options and free-text entries exhibited high retrieval rates, ranging from 91.7% to 100%. Standardised option common data elements were retrieved in all cases except for discharge destinations, which were documented in 91.7% of cases. Among the eight common data elements with free-text entries, five (underlying disease, symptoms after the accident, isolated traumatic brain injury, reasons for paediatric emergency department visit, reason for admission) had a 100% retrieval rate, while the remaining three (place and mechanism of accident, time interval between accident and paediatric emergency department visit) had retrieval rates ranging from 97.4% to 99.4% (table 1).

Data retrieval rates were 100% for the two common data elements without a defined documentation format (radiological examinations and neurosurgical interventions). However, documentation varied for the two variables not included in the common data elements: Glasgow Outcome Scale Extended and written discharge information. The Glasgow Outcome Scale Extended had a high retrieval rate of 96.7%, whereas data on written discharge information was available for 51.2% of outpatients and 53.3% of inpatients. The distribution of written discharge information to parents varied considerably between hospitals, ranging from 0 to 100% for both outpatients and inpatients (table 2).

Data collection efforts varied among different hubs, with the mean time investment per patient ranging from 0.5 to 2 hours. However, only the overall time effort was recorded, without distinguishing between parameters such as the workload required to determine a patient's eligibility for study inclusion. Eight of the ten hospitals completed this questionnaire. Among these, data retrieval per patient took up to 30 minutes in five hospitals, one-half to one hour in one hospital, and one to two hours in two hospitals. Only three hospitals involved their IT departments, which provided a computed screening list of traumatic brain injury patients based on diagnoses. The reasons for not involving the hospitals' IT departments and for nonparticipation of the two hospitals in the questionnaire were not specified.

# Secondary objectives

The prevalence of children treated for traumatic brain injury in paediatric emergency departments compared to all emergency department patients during the study period was 6%, with a range of 3% to 11.5% between hospitals. Most accidents occurred at home (48%, 165/344) or at the playground (18.9%, 65/344). Trauma mechanism was a fall in 196 cases (56.5%, 196/347): 124 (63.3%, 124/196) less than 1 metre, and only 2 (1%, 2/196) 3 metres or more. Impact against the head by another person or an object comprised 25.4% (88/347) of children, and 12.1% (42/347) were involved in traffic accidents, mainly while riding their bikes or scooters (76.2%, 32/42).

A normal GCS of 15 was observed in the majority of patients (99.1%) at admission, whereas a GCS of 14 was documented in four patients, and 13 and 3 in one patient each. In three cases, GCS scores deteriorated during the emergency department stay, with particular relevance in one case where a drop from 13 to 11 was observed and a CT scan revealed an epidural haemorrhage.

In the paediatric emergency departments, radiological examinations of the head were conducted in 12 cases (3.4%), including ten CT scans, one MRI, and one ultrasound. Among the CT scans, six were normal (all patients with a GCS of 15), and four were abnormal; one of the latter required surgery for an epidural haematoma resulting from a fall from an electric scooter. Another patient with a GCS of 3 following a two-metre fall had a subdural haematoma

Table 2:

Detailed information on demographics, severity level, and management of patients with traumatic brain injuries in the ten SwissPedNet hospitals (A to J).

		Α	В	С	D	E	F	G	Н	I	J
Patients with t	raumatic brain injury, n	96	60	40	38	27	23	21	21	12	11
Age, median (	IQR)	3.0 (2.0–6.0)	4.0 (1.25–6.0)	5.5 (1.0–10.75)	2.0 (1.0–5.0)	4.0 (2.0–9.0)	6.0 (4.0–11.0)	3.0 (1.5–9.5.0)	6.0 (2.0–9.0)	6.0 (1.75–13.75)	5.0 (1.0–8.0)
Prevalence (%	6)* of traumatic brain injury patients	8.2 (96/ 1167)	11.5 (60/ 521)	8.3 (40/ 483)	6.5 (38/ 583)	4.8 (27/ 562)	3.5 (23/ 654)	3.4 (21/ 619)	4.4 (21/ 472)	3 (12/395)	3 (11/ 370)
Triage scale,	Urgent (1–3)	33 (34.4)	10 (16.7)	4 (10)	14 (36.8)	6 (22.2)	11 (47.8)	3 (14.3)	5 (23.8)	3 (25)	6 (54.5)
n (%)	Non-urgent (4–5)	63 (65.6)	50 (83.3)	36 (90)	24 (63.2)	21 (77.8)	12 (52.2)	18 (85.7)	16 (76.2)	9 (75)	5 (45.5)
GCS score	15, n	92	60	38	38	26	23	21	21	10	11
	13–14, n	3	_	_	_	_	_	_	_	2	_
	3, n	1	_	_	_	-	-	_	-	_	_
	Missing data, n	-	_	2	_	1	-	_	-	_	-
CT scans in th	CT scans in the paediatric emergency department, n (%)		-	2 (5)	-	1 (3.7)	1 (4.3)	1 (4.8)	_	1 (8.3)	-
Hospitalisations, n (%)		9 (9.4)	12 (20)	11 (27.5)	9 (23.7)	1 (3.7)		4 (19)	1 (4.8)	11 (91.7)	2 (18.2)
Outpatients	Rate of written discharge information handed to parents, %	5.7 (5/ 87)	47.9 (23/ 48)	10.3 (3/29)	3.4 (1/ 29)	0 (0/26)	0 (0/23)	5.9 (1/17)	95 (19/ 20)	100 (1/1)	55.6 (5/ 9)
Inpatients	Rate of written discharge information handed to parents, %	11.1 (1/9)	25 (3/12)	0 (0/11)	0 (0/9)	0 (0/1)	_	75 (3/4)	100 (1/1)	90.9 (10/11)	50 (1/2)

CT: computed tomography; GCS: Glascow Coma Scale; IQR: interquartile range.

<sup>\*</sup> Prevalence (%) = (number of traumatic brain injury patients / total number of paediatric emergency department patients) × 100

but recovered without surgical intervention and was discharged after four days. Two patients exhibited clinical signs of basal skull fractures, which were confirmed through CT scans. The remaining radiological examinations provided no relevant additional information.

Among traumatic brain injury patients who received CT scans in the paediatric emergency department, lower triage numbers, loss of consciousness, and seizures were associated with a higher likelihood of a CT scan. Specifically, seizures and loss of consciousness increased the odds of receiving a CT scan by 30.45 and 18.84 times, respectively. As table 3 shows, no associations were observed for patient's age, GCS score, vomiting, amnesia, headache, or mental alteration.

Outpatient management was determined in 82.8% of traumatic brain injury patients (n= 289). Table 4 shows that lower triage numbers, loss of consciousness, and vomiting were associated with hospitalisation in traumatic brain injury patients. Loss of consciousness increased the odds for admission to the ward by 6.24, vomiting by almost 4 times (OR 3.98, 95% CI 1.94–8.16).

An analysis among the ten participating hospitals revealed variations in the prevalence of traumatic brain injury patients, the rate of CT scans performed in the paediatric emergency department, and the rate of inpatient management during the study week (table 2). These variations were observed among hospitals within the same region. All hospitals included children with urgent triage scales, but only two hospitals treated children with GCS of less than 15 during the study period. CT scans were performed in six paediatric emergency departments with rates from 3.7% to

8.3% among all traumatic brain injury patients. The rate of hospital admission for patients with traumatic brain injuries ranged from 0 to 91.7%.

### **Discussion**

This study aimed to assess the readiness for implementing SwissPedData within the ten SwissPedNet hospitals before its nationwide rollout. We found a data retrieval rate of over 90% for a broad spectrum of defined common data elements for traumatic brain injury patients, indicating that routine health care data is conscientiously documented in a structured manner, making it suitable for multicentre research. However, the time and effort required for data extraction were substantial, ranging from 0.5 to 2 hours per patient, which emphasises the need for additional technical support.

#### Data retrieval rates

Using patients with traumatic brain injury as an example, our study showed that most relevant data points for researchers were routinely collected and documented through the defined common data elements, aligning with their importance in clinical practice. Variability of the retrieval rates between hubs was low, demonstrating the adherence to data collection requirements despite, in some cases, very high time efforts. However, the accuracy and completeness of this data remain unknown, as they depend on the information provided by the parents and the physician's documentation in the electronic health record [19, 20]. Utilising standardised options instead of free text

Table 3:

Comparison and logistic regression analysis with adjusted and unadjusted odds ratios (OR) and 95% confidence interval (CI) for predicting computed tomography scans of traumatic brain injury patients treated in paediatric emergency departments. For binary variables, the mean represents the proportion of patients with the symptom, and the standard deviation (SD) reflects variability.

	CT scan (n= 10) mean (SD)	No CT scan (n= 339) mean (SD)	Unadjusted OR (95% CI)	Adjusted OR (95% CI)
Age in months	97.2 (60.2)	61.2 (51.7)	1.01 (1.00–10.22)	1.00 (0.98–1.01)
GCS score	13.4 (3.9)	15 (0.2)	0.30 (0.12–0.78)	0.74 (0.18–3.15)
Triage number	2.4 (1.4)	4 (0.9)	0.29 (0.16–0.52)	0.36 (0.17–0.74)
Loss of consciousness	0.6 (0.5)	0.06 (0.2)	22.71 (5.95–86.75)	18.84 (2.29–155.20)
Vomiting	0.5 (0.5)	0.2 (0.4)	3.78 (1.06–13.40)	2.53 (0.36–17.83)
Amnesia	0.1 (0.3)	0.04 (0.2)	2.40 (0.29–20.19)	0.58 (0.04–7.58)
Seizure	0.2 (0.4)	0.01 (0.1)	28.00 (4.10–191.31)	30.45 (1.88–492.44)
Headache	0.2 (0.2)	0.1 (0.3)	1.59 (0.33–7.73)	2.58 (0.30–22.11)
Mental alteration	0.1 (0.3)	0.07 (0.3)	1.40 (0.17–11.46)	1.16 (0.07–18.25)

CT: computed tomography; GCS: Glasgow Coma Scale.

Table 4:

Comparison and logistic regression analysis with adjusted and unadjusted odds ratios (OR) and 95% confidence interval (CI) for predicting hospitalisation of traumatic brain injury patients treated in paediatric emergency departments. For binary variables, the mean represents the proportion of patients with the symptom, and the standard deviation (SD) reflects variability.

	Inpatient (n= 60) mean (SD)	Outpatient (n= 289) mean (SD)	Unadjusted OR (95% CI)	Adjusted OR (95% CI)
Age in months	73.3 (65.8)	59.9 (48.7)	1.01 (1.00–1.01)	01.00 (0.99–1.00)
GCS score	14.6 (1.7)	15 (0.8)	0.13 (0.03–0.63)	0.24 (0.05–1.11)
Triage number	3.2 (1.2)	4.1 (0.9)	0.43 (0.32–0.57)	0.44 (0.31-0.63)
Loss of consciousness	0.2 (0.4)	0.04 (0.2)	6.46 (2.86–14.63)	6.24 (2.02–19.26)
Vomiting	0.4 (0.5)	0.2 (0.4)	3.66 (2.02-6.63)	3.98 (1.94–8.16)
Amnesia	0.1 (0.3)	0.03 (0.2)	4.11 (1.47–11.52)	1.52 (0.40–5.75)
Seizure	0.03 (0.2)	0.01 (0.4)	3.29 (0.54–20.11)	2.24 (0.20–25.48)
Headache	0.2 (0.4)	0.1 (0.3)	1.32 (0.62–2.82)	0.86 (0.33–2.27)
Mental alteration	0.2 (0.4)	0.06 (0.2)	2.82 (1.19–6.68)	2.21 (0.82–6.00)

GCS: Glasgow Coma Scale.

might improve data entry, ensuring that all defined common data elements are documented in patients' files; this is more structured and reduces the likelihood of missing important information [21].

In addition to the defined common data elements, our questionnaire contained common data elements with undefined formats for recording in the electronic health record, such as radiological examinations and surgery, as well as two variables not covered by the common data elements, the Glasgow Outcome Scale Extended and written discharge information. The rates of data retrieval differed markedly between these two categories. Information on radiological examinations and performed surgery was consistently documented, reflecting their significance in clinical practice. In contrast, data documentation for discharge information was poor, despite its critical importance in a paediatric emergency department setting for children with traumatic brain injury [22]. Our analyses cannot distinguish whether the discharge information was conducted but not documented or omitted altogether. Incorporating common data elements for discharge information could enhance data reliability, as data on discharge instructions hold high interest for quality control research [2].

Documenting changes in parameters over time is particularly crucial for researching conditions like traumatic brain injury or other potentially life-threatening diseases. To facilitate the analysis of repetitive data, such as Glasgow Coma Scale (GCS) scores over time, one potential solution could be incorporating timestamps into common data elements, a methodology used by PECARN for its registry [13]. Highlighting the significance of such recurring data, we analysed a patient in our cohort with an initial GCS of 13 who deteriorated during his emergency department stay, with a drop in GCS to 11, due to intracranial bleeding requiring emergency surgery.

The time required for data retrieval depends on the type of data collected. While the extraction of numeric data and information using standardised options is a straightforward process [1], obtaining valuable data from freetext entries requires considerable time [23]. However, we found that only three hubs involved their IT departments for this study, and their role was limited to providing screening lists of traumatic brain injury patients treated in the paediatric emergency departments during the study period. They did not provide numeric data or data with standardised options, which could have been easily extracted from the electronic health records. Instead, each patient's electronical file had to be analysed by the study coordinators to manually extract all data needed for this study. Whether IT support was unavailable or deemed unnecessary remains unknown. This time investment for data retrieval could pose a significant challenge, particularly for studies involving large sample sizes, where essential information related to accident details, symptoms, and reasons for hospitalisations is recorded as free-text entries within the context of SwissPedData. Manual extraction of data from free-text entries incurs a risk of inconsistent data retrieval as well as increasing workload [24]. As highlighted in prior research, either automated data extraction from clinical information systems (where technically feasible) or the use of named entity recognition tools, such as machine learning (ML), could improve data retrieval from free-text entries [25]. In a feasibility study (personal communication), one of the authors (MS) is currently analysing the benefits of ML for data extraction from free-text entries in electronic health records of patients presenting to the paediatric emergency department of the University Children's Hospital due to accidents, with promising results. Regardless of such technological advancements, closer collaboration with IT teams would be beneficial to streamline data retrieval pipelines.

# Patients with traumatic brain injuries

Addressing the broader context of traumatic brain injury research, our data align with international literature regarding age distribution of children with traumatic brain injury, trauma mechanism, and the injury severity rates of children treated in paediatric emergency departments [26–28]. The mean age of children with traumatic brain injury is 4 to 6 years; boys are more often affected, and the most common trauma mechanism is falls, followed by direct contusion of the head against an object and traffic accidents. The rate of CT scans in our study was lower than in international data with a rate of 3.4% compared to reported rates of 5.4% (Scandinavia), and 12.9% (US) [8, 26–29].

Factors associated with CT scans in Swiss hospitals included an urgent triage category, loss of consciousness, and seizures. All of these factors are part of the PECARN rules, which recommend a CT scan if any of them are present in children with mild traumatic brain injuries [30]. The PECARN rules derive from a multicentre study and are a clinical decision rule implemented to help physicians decide whether CT scans are required for children with mild traumatic brain injuries, with a primary goal of reducing unnecessary CT scans in those at very low risk of brain injuries [31]. International evidence has shown a reduction in CT scan rates when PECARN rules are applied. However, in Switzerland, CT scan rates are even lower because clinical observation is preferred over CT scans whenever possible [11]. Unlike the PECARN rules, our study found no association between CT scans and a GCS <15, altered mental status, or vomiting. As a result, more children in Switzerland were admitted to the ward for observation compared to other countries, where patients with normal CT scans are often discharged [31].

Data on the prevalence of traumatic brain injury in children vary widely due to differing methodologies and reporting standards [8, 25, 27]. Our dataset revealed an overall traumatic brain injury prevalence of 6% among children presenting to paediatric emergency departments, varying from 3 to 11.5% between hospitals. However, these values must be interpreted with caution, as only one week was analysed and differences in paediatric emergency department catchment areas must be taken into consideration. We also noted differences between hospitals regarding the rates of CT scans and hospital admissions. While CT rates in all hospitals were lower compared to international data, hospitalisation rates varied from 0 to 91.7%. Lower CT rates in mild traumatic brain injuries are associated with more hospitalisations, as demonstrated by Stopa et al.'s comparison of paediatric emergency departments in Boston and Trieste [32]. While the rates of CTs and hospitalisations in Boston reached 17.3% and 8.6%, respectively, the rates in Trieste were 6.6% and 55.7%. Beyond imaging practices,

factors influencing the decision to admit a patient with a mild traumatic brain injury include the child's general condition, severity of symptoms, time since the accident, and hospital guidelines (32). Differences observed in our study were not caused by regional disparities but rather by variations in hospital guidelines. Despite the absence of national guidelines for children with mild traumatic brain injury in Switzerland, institution-specific guidelines adapted to individual hospitals appear to be a valuable solution to further standardise treatment strategies on a national level.

#### Limitations

Our study has several limitations. First, the data (especially in the free-text fields) of the electronic health records were not qualitatively assessed for accuracy. Second, most paediatric emergency departments in Switzerland use noncoded diagnoses. Despite careful screening to avoid missing any cases, we cannot entirely rule out the possibility that some traumatic brain injury cases were overlooked. Third, due to the point-prevalence methodology and the variability in traumatic brain injury occurrences, the number of traumatic brain injury patients in our study might be over- or underrepresented. The majority of included patients had only mild traumatic brain injuries, this limits the generalisability for moderate and severe cases. It is also possible that children with severe traumatic brain injuries were directly admitted to intensive care units, leading to their underrepresentation in our cohort. Additionally, our study does not provide information on the long-term outcomes and potential sequelae of traumatic brain injury. However, our findings raise awareness of the high number of paediatric traumatic brain injury cases in Switzerland as well as national, evidence-based treatment standards. We hope that our study supports efforts in this direction. Finally, we only assessed the average time and effort needed for data extraction without detailed investigation into why IT support was involved only in certain hospitals.

Despite these limitations, our study supports the efforts to establish an electronic health record dataset for all Swiss paediatric hospitals, enabling multicentre research, and highlights the aspects that need to be considered for success.

# Conclusions

In conclusion, data retrieval was high for common data elements within clinical information systems for paediatric patients with traumatic brain injuries in paediatric emergency departments of ten children's hospitals, indicating readiness for the nationwide implementation of SwissPedData. However, considerable time and effort were required for extracting this data, underscoring the need for further standardisation of clinical information systems. Despite traumatic brain injuries as a common reason for paediatric emergency department presentations, they are generally mild in severity. Although no national guidelines for treating children with traumatic brain injuries exist in Switzerland, all hospitals demonstrated low rates of CT scans for children with traumatic brain injury and normal GCS.

# Data sharing statement

Due to the sensitive nature of the data and the small number of children with severe injuries in this study, we have decided not to share the data. While data and code sharing are encouraged in Open Science, it is essential to balance transparency with the protection of participant privacy and confidentiality. Detailed summaries of the findings can be made available upon request, and efforts will be made to ensure transparency in reporting while safeguarding participant confidentiality.

#### Acknowledgments

SwissPedNet consortium: clinical research network of ten Swiss children's hospitals (von Rhein Michael, Gualco Gianluca, Gualtieri Renato, Werner Claudia, Romano Fabrizio, Stritt Janine, Deak Csongor, Mack Alexander, Coulon Ludivine, Hauser-Angst Larissa, Seiler Michelle).

#### Financial disclosure

This study received no funding.

# Potential competing interests

All authors have completed and submitted the International Committee of Medical Journal Editors form for disclosure of potential conflicts of interest. No potential conflict of interest related to the content of this manuscript was disclosed.

#### References

- Rakic M, Jaboyedoff M, Bachmann S, Berger C, Diezi M, do Canto P, et al. Clinical data for paediatric research: the Swiss approach: Proceedings of the National Symposium in Bern, Switzerland, Dec 5-6, 2019.
   BMC Proc. 2021 Sep;15 Suppl 13:19. http://dx.doi.org/10.1186/ s12919-021-00226-3.
- Berry JG, Blaine K, Rogers J, McBride S, Schor E, Birmingham J, et al. A framework of pediatric hospital discharge care informed by legislation, research, and practice. JAMA Pediatr. 2014 Oct;168(10):955–62. http://dx.doi.org/10.1001/jamapediatrics.2014.891.
- Jaboyedoff M, Rakic M, Bachmann S, Berger C, Diezi M, Fuchs O, et al. SwissPedData: standardising hospital records for the benefit of paediatric research. Swiss Med Wkly. 2021 Dec;151(5152):w30069. http://dx.doi.org/10.4414/SMW.2021.w30069.
- Wismer AC, Rakie M, Kuehni CE, Jaboyedoff M, Romano F, Kopp MV, et al. Consensus Minimal Dataset for Pediatric Emergency Medicine in Switzerland. Pediatr Emerg Care. 2022 Oct;38(10):511–6. http://dx.doi.org/10.1097/PEC.0000000000002841.
- Mawji A, Li E, Chandna A, Kortz T, Akech S, Wiens MO, et al. Common data elements for predictors of pediatric sepsis: A framework to standardize data collection. PLoS One. 2021 Jun;16(6):e0253051. http://dx.doi.org/10.1371/journal.pone.0253051.
- Grinspan ZM, Patel AD, Shellhaas RA, Berg AT, Axeen ET, Bolton J, et al.; Pediatric Epilepsy Learning Healthcare System. Design and implementation of electronic health record common data elements for pediatric epilepsy: foundations for a learning health care system. Epilepsia. 2021 Jan;62(1):198–216. http://dx.doi.org/10.1111/epi.16733.
- Ward SL, Flori HR, Bennett TD, Sapru A, Mourani PM, Thomas NJ, et al. Design and Rationale for Common Data Elements for Clinical Research in Pediatric Critical Care Medicine. Pediatr Crit Care Med. 2020 Nov;21(11):e1038–41. http://dx.doi.org/10.1097/ PCC.00000000000002455.
- Al Mukhtar A, Bergenfeldt H, Edelhamre M, Vedin T, Larsson PA, Öberg S. The epidemiology of and management of pediatric patients with head trauma: a hospital-based study from Southern Sweden. Scand J Trauma Resusc Emerg Med. 2022 Dec;30(1):67. http://dx.doi.org/ 10.1186/s13049-022-01055-9.
- SwissPedNet. Quality Management of SwissPedNet. 2024. Available from: https://www.swisspednet.ch/header/quality-management
- STaR Child Health. Completed standards. 2024. Available from: https://www.starchildhealth.org/standards
- Menon DK, Schwab K, Wright DW, Maas AI; Demographics and Clinical Assessment Working Group of the International and Interagency Initiative toward Common Data Elements for Research on Traumatic Brain Injury and Psychological Health. Position statement: definition of traumatic brain injury. Arch Phys Med Rehabil. 2010 Nov;91(11):1637–40. http://dx.doi.org/10.1016/j.apmr.2010.05.017.

- Pardey TG. The clinical practice of Emergency Department Triage: Application of the Australasian Triage Scale—An extended literature review: Part I: Evolution of the ATS. Australas Emerg Nurs J. 2006;9(4):155–62. http://dx.doi.org/10.1016/j.aenj.2006.09.003.
- J Murray M. The Canadian Triage and Acuity Scale: A Canadian perspective on emergency department triage. Emerg Med (Fremantle). 2003 Feb;15(1):6–10. http://dx.doi.org/10.1046/j.1442-2026.2003.00400.x.
- Lyttle MD, Crowe L, Oakley E, Dunning J, Babl FE. Comparing CATCH, CHALICE and PECARN clinical decision rules for paediatric head injuries. Emerg Med J. 2012 Oct;29(10):785–94. http://dx.doi.org/ 10.1136/emermed-2011-200225.
- Deakyne Davies SJ, Grundmeier RW, Campos DA, Hayes KL, Bell J, Alessandrini EA, et al.; Pediatric Emergency Care Applied Research Network. The Pediatric Emergency Care Applied Research Network Registry: A Multicenter Electronic Health Record Registry of Pediatric Emergency Care. Appl Clin Inform. 2018 Apr;9(2):366–76. http://dx.doi.org/10.1055/s-0038-1651496.
- Wilson L, Boase K, Nelson LD, Temkin NR, Giacino JT, Markowitz AJ, et al. A Manual for the Glasgow Outcome Scale-Extended Interview. J Neurotrauma. 2021 Sep;38(17):2435

  –46. http://dx.doi.org/10.1089/ neu.2020.7527.
- Harris PA, Taylor R, Thielke R, Payne J, Gonzalez N, Conde JG. Research electronic data capture (REDCap)—a metadata-driven methodology and workflow process for providing translational research informatics support. J Biomed Inform. 2009 Apr;42(2):377–81. http://dx.doi.org/10.1016/j.jbi.2008.08.010.
- Harris PA, Taylor R, Minor BL, Elliott V, Fernandez M, O'Neal L, et al.; The REDCap consortium. Building an international community of soft-ware partners. J Biomed Inform. 2019;95:103208. http://dx.doi.org/ 10.1016/j.jbi.2019.103208.
- Wuerdeman L, Volk L, Pizziferri L, Tsurikova R, Harris C, Feygin R, et al. How accurate is information that patients contribute to their Electronic Health Record? AMIA Annu Symp Proc. 2005;2005:834–8.
- Hong CJ, Kaur MN, Farrokhyar F, Thoma A. Accuracy and completeness of electronic medical records obtained from referring physicians in a Hamilton, Ontario, plastic surgery practice: A prospective feasibility study. Plast Surg (Oakv). 2015;23(1):48–50. http://dx.doi.org/10.1177/229255031502300101.
- Ebbers T, Kool RB, Smeele LE, Dirven R, den Besten CA, Karssemakers LH, et al. The Impact of Structured and Standardized Documentation on Documentation Quality; a Multicenter, Retrospective Study. J Med Syst. 2022 May;46(7):46. http://dx.doi.org/10.1007/s10916-022-01837-9.
- Yengo-Kahn AM, Hibshman N, Bezzerides M, Feldman MJ,
   Vukovic AA, Mummareddy N, et al. Improving Discharge Instructions
   Following a Concussion Diagnosis in the Pediatric Emergency Depart-

- ment: A Pre-post Intervention Study. Pediatr Qual Saf. 2021;26;6(5):e456. http://dx.doi.org/10.1097/pq9.0000000000000456.
- Kenei J, Opiyo E. Modeling and Visualization of Clinical Texts to Enhance Meaningful and User-Friendly Information Retrieval. Med. Sci. Forum. 2023;10(1):9. http://dx.doi.org/10.3390/IECH2022-12294.
- Sheehan J, Hirschfeld S, Foster E, Ghitza U, Goetz K, Karpinski J, et al. Improving the value of clinical research through the use of Common Data Elements. Clin Trials. 2016 Dec;13(6):671–6. http://dx.doi.org/ 10.1177/1740774516653238.
- Landolsi MY, Hlaoua L, Ben Romdhane L. Information extraction from electronic medical documents: state of the art and future research directions. Knowl Inf Syst. 2023;65(2):463–516. http://dx.doi.org/10.1007/ s10115-022-01779-1.
- Langlois JA, Rutland-Brown W, Thomas KE. Traumatic brain injury in the United States: emergency department visits, hospitalizations, and death.2006 Centers for disease control and prevention. Available from: https://stacks.cdc.gov/view/cdc/12294/ced\_12294\_DS1.pdf http://dx.doi.org/10.1037/e721222007-001.
- McKinlay A, Grace RC, Horwood LJ, Fergusson DM, Ridder EM, Mac-Farlane MR. Prevalence of traumatic brain injury among children, adolescents and young adults: prospective evidence from a birth cohort. Brain Inj. 2008 Feb;22(2):175–81. http://dx.doi.org/10.1080/ 02699050801888824.
- Keenan HT, Bratton SL. Epidemiology and outcomes of pediatric traumatic brain injury. Dev Neurosci. 2006;28(4-5):256–63. http://dx.doi.org/10.1159/000094152.
- Shan J, Warton EM, Reed ME, Vinson DR, Kuppermann N, Dayan PS, et al. Computed Tomography Use in Children With Minor Head Trauma Presenting to 21 Community Emergency Departments Within an Integrated Health-Care System. Perm J. 2021;22;26(1):32-7.
- Sawaya RD, Wakil C, Wazir A, Shayya S, Berbari I, Safa R, et al. Does implementation of the PECARN rules for minor head trauma improve patient-centered outcomes in a lower resource emergency department: a retrospective cohort study. BMC Pediatr. 2020 Sep;20(1):439. http://dx.doi.org/10.1186/s12887-020-02328-x.
- Kuppermann N, Holmes JF, Dayan PS, Hoyle JD Jr, Atabaki SM, Holubkov R, et al. Identification of children at very low risk of clinicallyimportant brain injuries after head trauma: a prospective cohort study. Lancet. 2009;3;374(9696):1160-70. http://dx.doi.org/10.1016/ S0140-6736(09)61558-0.
- Stopa BM, Amoroso S, Ronfani L, Neri E, Barbi E, Lee LK. Comparison of minor head trauma management in the emergency departments of a United States and Italian Children's hospital. Ital J Pediatr. 2019 Feb;45(1):24. http://dx.doi.org/10.1186/s13052-019-0615-0.