

Registries for Research and Quality Management in Emergency Care

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Abstract. This article provides a review of German emergency registries which follow the overall objective of quality improvement in emergency care. The various registry projects are briefly presented and compared with regard to their objectives and specific field of emergency care. The aim is to create a basis for future registry projects with reference to aspects of methodology, data sources, and scope. The results show that none of the projects cover the whole emergency care chain in a comprehensive way, i.e., across the prehospital and clinical sector. This reveals the need for the establishment of a registry that spans over a broader range of the care chain, in order to analyse the patient- or case-based data along the complete emergency care process.

Keywords. Emergency medicine, emergency registry, literature and project review

1. Introduction

In medical research it is increasingly recognized that the collection and standardised processing of data offers immense added value for patient centred medical care. In German emergency care, many projects arose since the standardised collection of data is now settled in most of the emergency medical services (EMS) districts. Compared to global and European systems, German EMS are special since they are administrated by the local authorities. Thus there is a great variation of different EMS concerning coverage and internal organisation, which also leads to a decentralised organisation of medical data and strengthens the importance of standardised data collection through registries. This paper aims at comparing different emergency registry projects in order to gain insights in the state of the art in data set definition, data collection, and coverage of emergency care sectors.

2. Methods

The review included projects creating registries with data from emergency care, which focus on the two areas of EMS and the emergency department. An additional inclusion criterion was the existence of a well-defined target population, in this case specified by certain groups of emergency patients. The criteria for the review of the projects are

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divided in two categories. The first contains the project objectives and the second outlines the data set and data collection procedure that is intended to give conceptual and technical insights.

3. Review of emergency registry projects

3.1. Trauma registry DGU® (started 1993)

The Trauma Registry DGU® records approx. 90% of all severely injured persons in Germany. More than 300,000 cases have been recorded since its foundation. The registry enables the participating clinics to provide quality assurance in the field of trauma surgery. Based on the data, clinics can benchmark their own indicators in comparison with other clinics and optimization potentials can be recognized [1].

The data is collected from the four consecutive phases: (i) pre-clinic, (ii) trauma room and subsequent surgery, (iii) intensive care unit, and (iv) discharge. A total of around 100 variables are recorded for each case, a subset of 40 variables is mandatory for the members of the DGU® trauma network. In 2009, the European Utstein style [2] for the documentation of trauma patients was adapted. The registry includes patients who were admitted to the hospital via the trauma room with subsequent intensive care or reached the hospital with vital signs but died before admission [3].

The data acquisition is web-based via the Trauma Portal DGU®. The data is checked for plausibility by the system after input. More than 130 tests check for time sequences, min. and max. values, vital signs, data types, etc. In addition to manual data entry, it is also possible to transmit data electronically in the form of XML files from the hospital information system (HIS) [3].

3.2. German resuscitation registry GRR (started 2007)

The German Resuscitation Registry (GRR) is the largest supra-regional database for the collection, evaluation and assessment of resuscitation measures and intra-clinical emergency care in Germany. The database aims at optimising the quality of treatment for patients with cardiovascular disorders in emergency care. Since its inception, 110,000 data records of outpatients and reanimated patients were recorded. The aim is to increase the survival rates of patients with cardiovascular arrest through evidence-based quality management by doctors and EMS [4].

Already in 2003, a data set was developed for primary care, clinical follow-up and long-term course and tested it in a pilot project. Due to the new recording of emergency medical treatment by the minimum dataset for emergency physicians (MIND), the data set was revised in 2011 [5]. The data input is carried out by the treating EMS, hospital staff or the physician (after one year) through various systems for electronic data capturing.

The comparability of the resuscitation results is guaranteed by compliance with the specifications of the Utstein style [2]. The core data set includes the presumed cause, the location of the event, the first ECG rhythm derived and the possible success of the measures, whereby time points in the course of treatment also reflect important characteristic values. The online database can be viewed by participants in the registry and an anonymous benchmarking to evaluate the own performance is possible. More than 150 statistical evaluations allow for an own process analysis [4].

The data flow is initiated on the basis of the three entry scenarios initial care, clinical follow-up and long-term course (after one year). The protocol is filled manually or automatically as an XML file. After entry into the web application and storage in the database, the data can be used for scientific evaluation purposes [4].

3.3. SQR-BW (started 2011)

The project's objectives are to ensure the quality of the EMS in the German state of Baden-Württemberg, to identify potential for improvement, to develop measures for further optimisation and to guarantee sustainable support for all those involved in the EMS. The basis for this is provided by an integrative data model, which allows an objective comparison of the participants in the EMS on the basis of quality indicators [6].

The selection of data and indicators is based on a systematic review of scientific literature. This ensures that the indicators are valid, reliable and discriminatory. The operationalisation of the data determines which data are used and how they are collected and evaluated [6].

There are a total of 29 quality indicators, which are subdivided into the following areas: operation time flow, disposition quality, diagnostics and monitoring, care and transport as well as reanimation. The data basis for this is provided by the emergency operations carried out by the dispatch center, the emergency physician locations and the rescue stations. The supplying sources have certain data set specifications pre-defined. Since 2017, MIND3.1 is the minimum standard for EMS documentation [7].

To ensure complete, plausible and correct data, random sample protocols from the data source are compared with the export results. While the data from emergency physician and mobile intensive care unit (MICU) follow the MIND and thus share a common standard, the dispatch center data must be processed separately.

3.4. AKTIN (started 2013)

AKTIN is a Germany-wide emergency department registry that aims to improve the quality of emergency departments by collecting data according to the emergency protocol [8]. The underlying documentation standard is the emergency department data set of the DIVI, which is separated into different modules [9]:

- Basic (e.g., patient master data, admission date and time),
- Monitoring (e.g., measures),
- Trauma (e.g., cause and type of accident),
- Consil (e.g., time of day, doctor performing the procedure)
- Neurology (e.g., consciousness)
- Anesthesia supplement documentation (e.g. risk assessment, urgency)

The documented data is first stored in the HIS and exported into a clinical document architecture (CDA). As soon as a scientific data request is made, the CDA with the selected data is transferred to the AKTIN endpoint, where the verification of data is performed. If an error message occurs, the data is rejected and if the data is verified, it is imported into the local AKTIN data warehouse. The decentralized structure guarantees that the data remains in the individual hospitals [9].

3.5. INDEED (May 2017 to April 2020)

The project aims at retrospectively linking the treatment data of emergency department patients of one year (2016) from up to 20 emergency departments with billing data of the insurances two years before and one year after the emergency department stay. In the long term, the identification of gaps in care and of inadequate allocation of resources should take place. In addition, a model is to be developed in order to ensure a needs-based adaptation of care structures [10].

The registry collects data from statutory health insured patients who were treated in one of the 20 participating emergency departments. With an average of up to 34,000 patient encounters per year, the total sample size is 510,000 – 680,000 patients, allowing statistically representative analyses.

The data is processed, de-identified and encrypted in such a way that it can be merged with other participating emergency departments and health insurance billing data via record linkage. Identifying data are not disclosed at any point [11].

To implement this, identifying (IDAT) and medical data types (MDAT) are separated from each other. Within the hospitals, pseudonyms are created on the basis of the number of the electronic health card, as well as the name, first name and date of birth. The extracted data is forwarded to the central data management system via record linkage using the electronic health card and the personal pseudonyms. The linked pseudonyms are then replaced by a randomly generated ID in order to prevent traceability [11].

3.6. Inno_RD (April 2018 to June 2020)

The scope of the project is to create a database for emergency care at the patient level originating from four model regions. The aim is to empirically quantify the care processes in which the EMS is involved in order to develop outcome-based quality indicators for the EMS. The evaluation of these quality indicators allows to work out potential improvements in the organisation, financing, incentives and consequences of emergency care [12].

The EMS data are collected for the year 2016 and consist of dispatch center data, MICU data and emergency physician data, as well as billing data [12]. In addition, the data from eleven nationwide health insurance funds are included. This insurance data includes master data, data on incapacity to work, data on outpatient and inpatient treatment and data on medication regulations. As a follow-up to the emergency care process, interview-based surveys are planned, where 1,500 insured persons are to be reached. In a final step, focus group interviews with regional and national experts are intended. These interviews should legitimize the need for actions that base on results of the database by health care experts [12].

4. Results

The comparison of the emergency registry projects revealed, that they emphasize different sectors in the emergency care chain (see Table 1). Some projects such as the Trauma and the Resuscitation Registry cover a high degree of care sectors but are specified in a certain field of emergency. The projects that collect data from all emergency fields, focus either on prehospital data (e.g. SQRBW) or only on post EMS

data (e.g. AKTIN). Inno_RD seems to cover a large spectrum of care, but has a retrospective approach and does not continuously collect data.

Table 1: Coverage of the emergency care chain

	Dispatch Center	MICU	Emergency physician	Emergency department	Hospital ex e. d.	Insurance	Ex post* information
DGU		X	X	X	X		
GRR		X	X	X	X		X
SQRBW	X	X	X				
AKTIN				X			
INDEED				X		X	
Inno_RD	X	X	X			X	X

*Interviews (Inno_RD) and medical records after hospital stay (GRR)

5. Conclusion

There is still need for an emergency registry that covers all diagnostic fields of emergency care and at the same time the two most important fields of emergency care: the EMS and the emergency department. Accomplishing this would be an important step towards analysing the patient- or case-based data along the complete emergency care process.

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