20 years TraumaRegister DGU®: Development, aims and structure

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ABSTRACT

The TraumaRegister DGU® organisational and technical development has undergone an evolution process, which started 20 years ago. Currently, the management of the registry is under the management of the “AUC – Academy for Trauma Surgery” (infrastructure) and the “Sektion NIS” (scientific responsibility). The aim of the registry was to establish an inter-hospital quality assessment tool with the option to use the increasing database for scientific evaluations of acute care. Year after year and most recently with the obligatory participation of certified hospitals the number of participating hospitals has grown as well as the registered cases per annum. Recently, even hospitals from other countries joined the registry too. Starting with six German hospitals and 260 cases in 1993, 20 years later more than 600 hospitals from eleven countries deliver over 30,000 trauma cases per year resulting in over 150,000 reported cases until 2013. In this article a historical perspective is presented of the evolution and current status of the TraumaRegister DGU®.

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Introduction

The idea of developing a trauma registry to compare patient’s outcome despite very different injury pattern was created by a small group of enthusiastic trauma surgeons. They were inspired by the increasing discussion about scoring systems in trauma in the eighties and the results of the Major Trauma Outcome Study published a few years before [1]. They founded a working group of the German Trauma Society in 1992 originally called “AG Scoring”. After a few consensus meetings they came to terms with a documentation sheet and started to document the first patients in the following year. The aim of this group was to establish an inter-hospital quality assessment tool with the option to use the increasing database for scientific evaluations of acute care. Just six German hospitals took part in this group in the beginning.

Since the topic of the working group was not only scoring but also evaluating acute care of severely injured patients the working group was renamed to “AG Polytrauma”, the German term for severely injured patients. In 2007, the working group merged with the working group on “Emergency medicine” to form the “Committee on Emergency Medicine, Intensive Care and Trauma Management” of the German Trauma Society (“Sektion NIS”). This committee took the scientific responsibility for the further development of the TraumaRegister DGU® (TR-DGU) coordinated by a “TraumaRegister Steering Group” within this Committee. Today the TraumaRegister DGU® covers about 90% of all severely injured patients in Germany, at eye level with a handful of other national trauma registries in the world.

Development of the dataset

The treatment of severely injured patients can be divided into four consecutive time phases: the time from accident until admission to hospital (pre-hospital phase), the time from admission to the emergency room until admission to ICU or ward, including initial operations (ER/OP phase), the time while on ICU, and finally the time until discharge from acute care hospital. For all four phases parameters are needed, which illustrate the condition of the patient in this phase and describe their treatment. Finally, the outcome has to be documented, and this is more than just survival.

Other parameter should also cover topics like epidemiology (e.g. type of accident), injury severity and pattern, process of care data (e.g. time until certain diagnostics are performed), and finally some characteristics of the treating hospital. In order to guarantee completeness of data it is an advantage if these variables are documented routinely. However, the decision to include a variable in the registry should not exclusively depend on its routine availability. For an overview of the currently used variables see Table 1. The documentation form itself is available in German and English at www.traumaregister.de.
For description of the injuries the Abbreviated Injury Scale (AIS) was chosen, which is the basis for calculating the Injury Severity Score (ISS) and the New Injury Severity Score (NISS). These scores are the worldwide standards for reporting severely injured patients despite some limitations. During the last 20 years, the AIS has been updated repeatedly and the TR-DGU followed these updates. The TR-DGU started with the 1990 version and implemented the 1998 update as soon as it became available. The actually used version is the 2005/08 version (there were only minor changes in the 2008 version as compared to 2005). However, the large number of participating hospitals does not allow providing an adequate coding training for all participants. Therefore, in 2009 when the new online documentation software was developed, a reduced version of the AIS 2005 with only 460 injury items was introduced. This reduction was possible due to numerous detailed injury descriptions (codes) with the same severity level. Such codes were merged into a single code, conserving the appropriate severity descriptor.

The TR-DGU dataset is permanently being discussed in the steering group. Every three to four years, an update of the dataset was published (realised in 2002, 2005, 2009 and 2014). Such updates include, for example, new developments in trauma care like the more specific description of treatment of coagulopathy. The overall workload for documentation, however, is also a permanent criterion to be considered.

The TR-DGU actually collects about 100 different data items for each case (depending on the number of injuries). With founding of the TraumaNetzwerk DGU®, a short version of the dataset was developed to meet only the minor demands of a quality assessment tool (TR-DGU QM form). This dataset contains about 40 variables focussing on the structural data of the patient management. Certified hospitals of TraumaNetzwerk DGU® are obligated to use the QM form at least, but asked for using the standard form.

In 2009, the TR-DGU dataset was also adapted to the Utstein European Core Dataset for documentation of trauma patients [2]. This 30 items core dataset has been developed by several European trauma registries including the TR-DGU using formal consensus methods. Also the “QM form of TR-DGU” dataset meets these conditions.

### Inclusion criteria

It was looked for an inclusion criterion that enables a decision already within the emergency room in the first minutes without the need for calculating severity scores (AIS, ISS, etc.), diagnostic results, vital or laboratory values. Thus the definition “admission via emergency room and the potential need of intensive care” was adopted as inclusion criterion. In 2013 the criterion was sharpened to the following definition: “The TraumaRegister DGU® aims to enrol all patients, who either have been admitted to hospital via emergency room with subsequent ICU/ICM care, or reach the hospital with vital signs and die before admission to ICU/ICM.” This definition of cases aims to include the more severe cases only, since in these cases a hospital’s ability to adequately manage trauma patients is expected to become particular apparent. On the other hand, the effort needed for documentation is limited by this definition since the large number of cases with minor injuries is disregarded. We also defined some exclusion criteria, mainly because these patients could not adequately be described (e.g., prognosis), or they require specific interventions that lie outside the scope of the registry. Such cases are patients dead on arrival, burns, hangings, drowning, and poisonings. There were no limitations on age, i.e. children are included as well.

Using these inclusion criteria, the mean ISS of all patients is 17 points; with 48% of cases having an ISS ≥ 16 (data are based on 28,805 cases from 2012). The mean age was 47.6 years, and 70% of cases were males. Only 5.1% of cases suffered from penetrating trauma, while traffic accidents were the leading cause of injury with 55%.

### Organisation and financing

In the first years the financial burden for developing and maintaining the infrastructure for the registry was bore by the interested surgeons and their hospitals. In 1996 financial support by the German Research Foundation (Deutsche Forschungsgemeinschaft, DFG) could be attained for six years. The support included several positions for specialists like documentation assistants, a statistician, an economist, and psychologists. One of the results of this research fund was a questionnaire for assessing quality of life in severely injured patients called POLO Chart [3]. During that time, completed data sheets of all participating hospitals were sent to one of three centres. Then data were entered into a local database that was merged with the two existing others once a year.

When the research fund ran out documentation of cases had to be shifted to the participating centres by a web-based interface for data entry (see also technical development). In the following years some grants from companies helped the registry to survive, besides the ongoing support of universities and individuals.

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**Table 1**

Current used variables. CPR, cardiopulmonary resuscitation; CT, computed tomography; CCT, cranial CT; FAST, focused assessment with sonography in trauma.

<table>
<thead>
<tr>
<th>S</th>
<th>Patient</th>
<th>A Pre-hospital phase</th>
<th>B ER/OR phase</th>
<th>C Intensive care unit (ICU) phase</th>
<th>D Outcome and discharge</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td>Arrival and departure of ambulance</td>
<td>Date/time of arrival</td>
<td>Date/time of admission</td>
<td>Outcome (death, survival)</td>
</tr>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td>Mode of transportation</td>
<td>Transfer</td>
<td>Vital signs</td>
<td>Date/time of discharge or death</td>
</tr>
<tr>
<td><strong>Prior diseases</strong></td>
<td></td>
<td>Vital signs</td>
<td>Glasgow Coma Scale</td>
<td>Initial lab values</td>
<td>Discharge destination</td>
</tr>
<tr>
<td><strong>Date/time of accident</strong></td>
<td></td>
<td>Glasgow Coma Scale</td>
<td>Pupils</td>
<td>Haemostasis treatment</td>
<td>Glasgow Outcome Scale</td>
</tr>
<tr>
<td><strong>Mechanism (blunt/penetrating)</strong></td>
<td></td>
<td>Suspected injuries</td>
<td>Vital signs</td>
<td>Sepsis</td>
<td>Thromboembolic events</td>
</tr>
<tr>
<td><strong>Type of accident (traffic, fall, etc.)</strong></td>
<td></td>
<td>Therapy:</td>
<td>Initial lab values</td>
<td>Organ failure</td>
<td>Complete list of AIS injury codes</td>
</tr>
<tr>
<td><strong>Cause of accident</strong></td>
<td></td>
<td>- Intubation</td>
<td>Diagnostics:</td>
<td>Duration of intubation</td>
<td>Surgical interventions (per injury)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Sedation</td>
<td>- CT</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Chest tube</td>
<td>- CCT</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>- CPR</td>
<td>- FAST</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>- Vasopressor therapy</td>
<td>- X-ray</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>Volume (amount by type)</td>
<td>Emergency surgery</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Blood transfusion</td>
<td>First surgical intervention</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>Haemostasis treatment</td>
<td>Therapy</td>
<td></td>
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</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Volume (amount by type)</td>
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</tbody>
</table>

**Note:**

For each type of injury the Abbreviated Injury Scale (AIS) was chosen, which is the basis for calculating the Injury Severity Score (ISS) and the New Injury Severity Score (NISS). These scores are the worldwide standards for reporting severely injured patients despite some limitations. During the last 20 years, the AIS has been updated repeatedly and the TR-DGU followed these updates. The TR-DGU started with the 1990 version and implemented the 1998 update as soon as it became available. The actually used version is the 2005/08 version (there were only minor changes in the 2008 version as compared to 2005). However, the large number of participating hospitals does not allow providing an adequate coding training for all participants. Therefore, in 2009 when the new online documentation software was developed, a reduced version of the AIS 2005 with only 460 injury items was introduced. This reduction was possible due to numerous detailed injury descriptions (codes) with the same severity level. Such codes were merged into a single code, conserving the appropriate severity descriptor.
The real breakthrough for the registry came with the society’s publication of a White Book [4] in 2006 where it is suggested to organise trauma care in local networks (see the article of Ruchholtz et al. about trauma networks in this issue). Besides introducing an audit process and defining structural requirements it was the decision to use the TraumaRegister DGU® as an obligatory tool for quality assessment which caused an enormous increase in participants. The AUC – Academy for Trauma Surgery (100% subsidiary and economic entity of the “German Trauma Society”) (Deutsche Gesellschaft für Unfallchirurgie e.V., DGU) took over

**Fig. 1.** The first documentation form was published in 1993.
the responsibility for maintaining and further developing of the infrastructure and the operation of the database server, the database itself, and the web-based data entry application (TraumaPortal DGU, for more details see Technical development). For participation at TR-DGU a yearly fee of 500 € was introduced. This decision directed to a stable financial basis with own staff and a secure future sixteen years after founding the TR-DGU. Actually it takes three full-time positions to run the registry (excluding software development).

**Quality reports and annual meetings**

In the first years after starting data entry there were no formal reports but just some presentations of comparative

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**Fig. 2.** In the first years the hand-filled sheets were collected in one of the three data centres and entered in a Clipper application.

**Fig. 3.** The first web application was introduced in 2002.
results. Since 1998 structured annual reports were generated and issued to each participating hospital. These extended reports developed over time and still exist today as a 30 pages filling booklet with details about every phase of trauma care. Comparisons are performed within the same hospital over time, with other hospitals, and with the registry as a whole. These reports are handed over to the participants at an annual meeting with presentation of further developments of the registry and results from scientific analysis.

In order to more quickly feed back the results to the participants, an automatically generated report was included with the software update in 2009. This six-page document (PDF format) can be requested at any time, and analyses are based on the actual number of completed cases. Besides the large annual meeting the TraumaRegister Steering Group meets once a year for a working weekend in the insularity of a former seminary. In this two-day meeting the further development of the registry is discussed, e.g. adaptations of the existing dataset and the inclusion criteria, the control of data use (publication guideline), quality indicators, co-operations with other registries and organisations, integration of new modules (quality of life after trauma, rehabilitation). Results of this discussions and realised implementation are reported twice a year to the meetings of the Sektion NIS, the scientific board of the TR-DGU.

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### Technical development

The data collection started with a rather simple paper documentation form (Fig. 1). These forms have been sent once a year to the hospital in Cologne. Data had to be entered by hand into a self-written Clipper application with plausibility checks based on an xBase database (Fig. 2). In 1998 due to the rising number two further centres for data entry were announced (Essen and Hannover). The three separate data files then were joined once a year to generate the annual reports for the hospitals and to conduct scientific analyses.

In 2002, when the research grant expired (see “Organisation and financing”) there were no more resources for this kind of time-consuming data management, also regarding the ever increasing number of participating hospitals. So a web-based data entry application was developed (Fig. 3). This tool contained a large number of plausibility checks in order to improve data quality. An advanced user management gave the hospitals the opportunity to enter their data by themselves. A central database server was bought and hosted at one of the participating university hospitals and administrated from one of the members of the working group TraumaRegister.

In 2009 this situation was transformed into a state-of-the-art server hosted at a professional data centre with own staff for administration. Also the software was rewritten (Fig. 4) and

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**Fig. 4.** In 2009 the web application was rewritten and re-launched with new design.
integrated into the TraumaPortal DGU, which then serves as a platform for all certifying processes (TraumaNetzwerk DGU®) and registry entries (TraumaRegister DGU®). With the new software also new services, e.g. automatic reports and statistics could be offered to the hospitals. Beside the manual data entry also an electronic data submission via xml was introduced to import data directly from the hospital information system. The data entry software was made available in German and English language and designed for an easy introduction of further languages.

Data quality

For obtaining a high data quality and minimising errors while data entry a high number of possibility checks are applied. In the moment more then 130 checks control for time series, minimum and maximum values of labour values and vital signs, logic of indicated measurements, data types (numbers vs text), etc. These checks are also performed while electronically import of the patient data. The possibility checks are under continuously improvement/development. Besides improving the web application also on-side checks of the correctness of the reported data are performed. At the beginning carried out in the context of medical dissertations [5–7] with introduction of the TraumaNetzwerk DGU® a randomised control of the health records is a general element of the re-auditing process for the hospitals.

Participating hospitals and case numbers

After the first year of data collection the six hospitals had delivered 260 trauma cases. Only five years later already 25 hospitals delivered 1211 cases to the registry, so more then 4000 cases were included in this time. This steady rising in numbers of cases and participating hospitals could be observed until 2008, when with the foundation of TraumaNetzwerk DGU® and the obligatory participation of the certified hospitals produce a distinct rise in numbers in the following years (Fig. 5). In 2013 more than 600 hospitals reported over 33,000 trauma cases (Fig. 6). The majority of these hospitals are from Germany and with only a few regions left, giving a nearly representative view of trauma care in Germany. With the end of 2013 more the 150,000 trauma cases were reported to the registry since its founding 20 years before.

Internationalisation

Originally intended as a registry for German hospitals, the first non-German hospital (from Switzerland) joined already two years after founding. In 1998 the first Austrian and in 2002 the first
A Dutch hospital followed. Since then also hospitals from Belgium, China, Finland, Luxembourg, Slovenia, and the United Arab Emirates participated. This hospitals joined as independent trauma centres, or were included as part of a cross-border trauma network (TraumaNetzwerk DGU¹). With an increasing number of non-German participants it becomes possible to compare differences of rescue systems and of in-hospital trauma care between the participating countries. As a good example for this, a comparison between Germany and the Netherlands is contained in this issue (see Timm et al. in the same issue). Together with the implementation of the European Core dataset (see above) these are the first steps towards a European trauma registry.

**Scientific output**

Besides the inter-hospital assessment of quality of care the anonymised data of the registry are increasingly used to analyse scientific questions and to generate and test hypotheses. Starting with the first scientific publication in 1994 up to now more than 230 scientific publications could be generated using data of the registry. In the first years most of the publications were published in German journals, but now the majority is published in English. For an overview of the development of the scientific performance see Fig. 7.

**Time line**

A summary with the important milestones for the registry is presented in Fig. 8.

**Further information and participation**

For further information see also www.traumaregister.de. There can be found all documentations sheets, the general versions of the annual reports, lists of participating hospitals and conditions for attending the registry and other information.
Conflict of interest

Professor Rolf Lefering has an ongoing consultancy and service agreement with the AUC GmbH, which is owner of the TR-DGU. He is also member of the Committee on Emergency Medicine, Intensive Care and Trauma Management of the German Trauma Society (Sektion NIS) where he leads the TR-DGU steering group together with Dr. Thomas Paffrath. Dr. Thomas Paffrath is deputy head of the Committee on Emergency Medicine, Intensive Care and Trauma Management of the German Trauma Society (Sektion NIS) where he leads the TR-DGU steering group together with Professor Rolf Lefering.

Ulrike Nienaber is staff member at AUC – Academy for Trauma Surgery.

Acknowledgments

This manuscript was written by Ulrike Nienaber (AUC – Academy for Trauma Surgery) together with Dr. Thomas Paffrath (Cologne Medical Centre) and Professor Rolf Lefering (IFOM) as head of the steering group TraumaRegister DGU.

References