

Developing a decentralized emergency care research database for Germany

Janko AHLBRANDT^b, Dominik BRAMMEN^a, Martin KULLA^c,
Rainer RÖHRIG^b, Sylvia THUN^d, Felix WALCHER^e

^a *Department of Anaesthesiology and Intensive Therapy, University Hospital Magdeburg*

^b *Medical Informatics in Anaesthesiology and I.C., Justus-Liebig-University Giessen*

^c *Department of Anaesthesiology and Intensive Care Medicine - German Armed Forces Hospital Ulm*

^d *Faculty of Health Care, University of Applied Sciences Niederrhein*

^e *Trauma-, Hand- and Reconstructive Surgery, University Hospital Frankfurt*

Background

Interdisciplinary emergency rooms in Germany have been evolving in recent years. Today, more than 1000 emergency departments take care of about 21 million emergency patients [1]. Unfortunately, data for benchmarking analysis, quality management or health surveillance is rare, especially in contrast to international literature [2]. In other countries, registries routinely collect emergency care data [3]. German data privacy laws prohibit centralized collection of broad sets of emergency care data without patients' informed consent or sufficient anonymization.

Goal

The aim of the project is to design and evaluate a decentralized emergency care research database. It will gather data from primary documentation systems and comply with German data privacy laws.

Results

The DIVI standardized emergency room core data set forms the basis [4] for the research database. Consented and published in year 2010, the data set and six reference paper protocols implementing it are standardized regarding medical semantics. However, they are not standardized regarding information processing and data management. In a first step, the protocols are to be encoded (or semantically annotated) with different terminologies like SNOMED CT, LOINC or OID. Using HL7-CDA, the protocols will be modelled so that the content is both human-readable and can be electronically processed, thus creating semantic interoperability. A decentralised emergency data warehouse will be designed according to the HL7-CDA-protocols and be implemented in i2b2 with a single hive for importing the data. The preferred means for importing will be HL7 version 3 messages in CDA style. For legacy purposes, we will also employ an existing importer for HL7 version 2 messages, if the observations within the messages are properly annotated using coding systems like LOINC or SNOMED-CT. This emergency data warehouse will be implemented at 15 participating model hospitals and the emergency-CDA-protocols will be imported in the data warehouse automatically. By this, a database with standardized data structure is generated in participating hospitals and will be connected to a centralized query infrastructure. According to German data privacy laws, only a non-identifying, anonymized subset of the emergency care protocol can be retrieved at a time. A researcher will have to get his data retrieval application reviewed by a board for ethical, scientific and data privacy means. After passing, a query will be formulated and sent to the participating decentralized data warehouses. After local approval, the data will be sent back to an independent data collector and there checked for sufficient anonymization. Finally the data will be handed to the researcher.

Discussion:

The core emergency dataset in combination with the clinical terminology and HL7-CDA standard is a comprehensive reference set for a national register [5]. The use of standard terminologies for the routine documentation in the emergency department makes data reusable for research. By this, the composition of an automated bio-surveillance system [6] or benchmarking analysis [7] should be possible. Using decentralized data warehouses over an asynchronous central IT-Infrastructure [8] with massive data reduction and guaranties for degrees of anonymity, we hope to meet German data privacy requirements.

- [1] T. Schöpke and T. Plappert, "Kennzahlen von Notaufnahmen in Deutschland," *Notfall + Rettungsmedizin*, vol. 14, no. 5, pp. 371–378, Jul. 2011.
- [2] S. Blaschke, G. A. Müller, and G. Bergmann, "[Reorganization of the interdisciplinary emergency unit at the university clinic of Göttingen].," *Anesthesiol. Intensivmed. Notfallmed. Schmerzther.*, vol. 43, no. 4, pp. 314–7, Apr. 2008.
- [3] J. M. Williams, J. H. Greenslade, J. V McKenzie, K. H. Chu, A. F. T. Brown, D. Paterson, and J. Lipman, "A prospective registry of emergency department patients admitted with infection.," *BMC Infect. Dis.*, vol. 11, p. 27, Jan. 2011.
- [4] F. Walcher, M. Kulla, S. Klinger, R. Röhrig, H. Wyen, M. Bernhard, I. Gräff, U. Nienaber, P. Petersen, H. Himmelreich, U. Schweigkofler, I. Marzi, and R. Lefering, "[Standardized documentation in emergency departments with the core dataset of the DIVI].," *Unfallchirurg*, vol. 115, no. 5, pp. 457–63, May 2012.
- [5] D. P. Hansen, M. L. Kemp, S. R. Mills, M. A. Mercer, P. A. Frostdick, M. J. Lawley, and S. U. P. P. L. E. M. E. Nt, "Developing a national emergency department data reference set based on SNOMED CT.," *Med. J. Aust.*, vol. 194, no. 4, pp. S8–10, Feb. 2011.
- [6] J. I. Tokars, R. English, P. McMurray, and B. Rhodes, "Summary of data reported to CDC's national automated biosurveillance system, 2008.," *BMC Med. Inform. Decis. Mak.*, vol. 10, p. 30, Jan. 2010.
- [7] U. Ekelund, L. Kurland, F. Eklund, P. Torkki, A. Letterstål, P. Lindmarker, and M. Castrén, "Patient throughput times and inflow patterns in Swedish emergency departments. A basis for ANSWER, A National SWedish Emergency Registry.," *Scand. J. Trauma. Resusc. Emerg. Med.*, vol. 19, p. 37, Jan. 2011.
- [8] A. J. McMurry, S. N. Murphy, D. MacFadden, G. Weber, W. W. Simons, J. Orechia, J. Bickel, N. Wattanasin, C. Gilbert, P. Trevvett, S. Churchill, and I. S. Kohane, "SHRINE: enabling nationally scalable multi-site disease studies.," *PLoS One*, vol. 8, no. 3, p. e55811, Jan. 2013.