

The Need for an International Medical Emergency Dataset

Judith Born, Jan Wohlmann and Christian Juhra
Office for eHealth, University Hospital Muenster, Germany

Keywords: Medical Emergency Dataset, epSOS, JAseHN.

Abstract: A significant number of problems in emergency care are caused by a lack of provider access to pre-existing patient information at the point of care. A particular difficulty is the access to information on the medical history of patients from other countries. This is due to a number of reasons such as language barriers, technical and safety hurdles, differences in expectations concerning content of the data and workflow differences between emergency room departments. With increasing numbers of travellers, a cross-national information exchange of relevant medical data in case of emergency is becoming more and more important. Therefore, this paper aims to discuss possibilities and requirements for setting up an internationally available emergency data set.

1 INTRODUCTION

Pre-existing medical information about patients is critical to first responders and physicians in delivering emergency services (Born, 2016). Unfortunately, this vital data is often unavailable to providers due to language or geographical barriers, or due to patient incapacitation (Shapiro, 2007). This is even more important for patients who need to be treated in another country. The number of airplane passengers in 2018 exceeded 4 billion and is expected to double by 2036 (IATA, 2019). With increasing numbers of travellers, the number of patients that need to be treated abroad will also rise.

In order to treat medical emergencies effectively and efficiently, the attending emergency physician must have certain background information about the patient, such as prior or acute diagnosis, medications, allergies, implants, etc.

Even when prior medical records are available in a specific country, they can be hard to access in a timely fashion and may have incomplete or difficult to interpret data (Shapiro, 2007). Some countries have implemented electronic medical records (EMRs) to improve accessibility of medical records to care providers. Yet, these records are uncommonly organized to provide the most essential information about the patients to be rapidly accessible to health providers in emergencies to guide optimal care.

Even if such emergency electronic datasets exist in one country, these data commonly cannot be accessed by an emergency physician in another country. Thus vital information can only be retrieved by laborious efforts (e.g. calling the physician in the home country) or not at all.

This position paper addresses the important questions why it is still not possible to access vital information in medical emergencies for international patients and what actions should be undertaken to resolve this issue.

2 PREREQUISITES FOR DATA EXCHANGE AND CURRENT STATUS

If medical data should be accessible and usable in case of an emergency in a foreign country, based in the experiences of the authors the following prerequisites must at least be met:

1. The data must valid, ie. it needs to be generated by a physician or other healthcare professionals.
2. The data must be stored electronically.
3. The data must be stored in a standardized format.
4. The data must be accessible in a secure way.
5. The data must be understandable for a foreign physician.

2.1 Electronic Medical Records in European Countries

In 2016 we conducted an internet research to identify current activities in deploying emergency datasets in European countries (all 28 Member States of the European Union as well as for Norway, Switzerland, Macedonia, Montenegro, Serbia, Albania, Bosnia and Herzegovina). The research was undertaken in English and German and excluded commercial approaches (such as medical emergency datasets included in the operating system of smartphones). The following table 1 shows all the initiatives that could be identified in this search. Due to the limitation of the search to German and English, the presented results do not claim to be complete.

Table 1: Emergency Datasets / EMRs Initiatives in Europe.

Country	Initiative
Germany	Emergency Dataset for the German Electronic Health Card
Switzerland	Emergency Medical Data for the Insurance Card
Austria	Emergency data for the Austrian electronic health records (ELGA)
England	Summary Care Record
Scotland	Emergency Care Summary
Northern Ireland	Emergency Care Summary Record
Wales	Individual Health Record
Norway	National Summary Care Record
Sweden	National Patient Overview (Nationell Patientöversikt)
Slovakia	Patient Summary (pacientsky sumar)
Spain	Patient Summaries (Historia Clínica Resumida)
Finland	National Patient Summary
Belgium	Summary Electronic Health Record (SumEHR)
France	Medical Component Summary (Volet Médical de Synthèse)

Despite the various activities in different countries to implement an EMR, an international exchange of medical data will only be possible if a standardized data format exists.

2.2 Standardization / Data Exchange

In order to facilitate medical data exchange across Europe, the epSOS (European Patients Smart Open Services)-project was initiated in 2008. Its goal was to develop a practical eHealth framework and ICT

infrastructure (based on existing national infrastructures) that will enable secure access to patient health information, particularly with respect to a basic patient summary and ePrescription, between European health care systems. The epSOS Consortium was composed of about 50 beneficiaries from 25 states, industry teams, as well as observers (including Bulgaria, Iceland, Lithuania, Serbia).

In order to provide the Health Care Professional (HCP) with a dataset of key health information at the point of care to deliver safe patient care during unscheduled care and planned care – having its maximal impact in the unscheduled care – the electronic Patient Summary was developed in epSOS.

A great achievement of the project was an identification of the most serious problems that currently impede cross-border transfer of patient data in an electronic form: the differences in national laws and semantic interoperability. For more information on the epSOS-project, which ended in 2014, please refer to (epSOS, 2014)

One of the follow-up projects of epSOS was the JAseHN (Joint Action to support the eHealth Network) project, which aimed to Develop political recommendations and other instruments for cooperation in four different areas:

1. interoperability and standardization
2. monitoring and assessment of implementation
3. exchange of knowledge and
4. global cooperation and positioning

During JAseHN, a report on Patient Summary guidelines' implementation was created based on the answers of representatives of 28 Countries, responsible for the implementation of these guidelines. According to JAseHN 13 out of these countries had no National Contact Points (NCPs) for the purpose of ensuring interoperability across national borders with other Member States. Seven countries had such NCPs, but they did not operate as suggested by the Patient Summary Guidelines. Only four countries had an NCP which role was set up and operated as suggested by these guidelines. So more than 10 years after the start of epSOS, most European countries still do not have an NCP and the needed infrastructure to support interoperability across borders.

Asked for the reasons for this, the countries answered:

- Other, more urgent, eHealth priorities (15)
- Other, more urgent, healthcare priorities (12)

- Organizational hurdles (12)
- Lack of data completeness (7)
- Technical hurdles (7)
- Lack of a clear national business case for implementing the Patient Summary guidelines (6)
- Lack of a clear financing procedure (6)
- Difficulty in changing current legal model (5)
- Low data quality (5)
- Lack of clinical acceptability of the Patient Summary guidelines (5)
- Lack of national sponsorship (4)
- Resistance and criticism from national stakeholders (4)
- Unclear or scattered responsibility (4)
- Burdensome existing IT systems (3)
- Reconcilability of professional terminologies is not possible (2)
- Nothing from the above (1)
- There were no problems faced. Implementation went without noticeable issues (1)

So for most countries, international exchange of medical data was not a priority and thus - so far - not implemented.

For more information on JAseHN, please refer to (JAseHN, 2019)

2.3 Accessibility and Security

Even if a national EMR is able to export medical data in a standardized way such as the epSOS Patient Summary, the data must still be accessible by international physicians. While within a national context, the accessibility of medical data can be restricted to registered health professionals, there is no way to ensure this on an international level. In addition, the patient can be unconscious and not able to provide access to his data by entering a secure code.

This dilemma between accessibility and security cannot be solved easily. Data could be accessed using QR-codes, which at least allows an international physician to view the data or even import it into his own information system. These QR-codes must be easy to find by an emergency physician should the patient be unconscious. For example, it could be printed and stuck to the health insurance card. However, using only a QR-code would provide access to anyone who gets hold of this code. This could of course be wanted by the patient, but a second layer of security would strongly be recommended.

2.4 Understandability

Working with international patients, speech barriers will often arise. How would a French emergency physician be able to understand a Swedish Emergency Dataset? Since the European Union has 24 official languages, even in the EU it will be difficult to ensure that each Emergency Dataset will be understood by each emergency physician.

The use of codes such as ICD-10 will also not solve this problem, since the evaluation of the German Medical Emergency Dataset showed that more medical information was included in the text field than in the according ICD-10-GM codes (Born, 2015). The use of SNOMED CT might help solving this issue. SNOMED CT is a comprehensive, multilingual clinical healthcare terminology with scientifically validated content and the aim to enable consistent representation of clinical content in electronic health records. Furthermore it is mapped to other international standards. For more information on SNOMED CT, please refer to (SNOMED International 2019).

However, not all countries do have a nation-wide SNOMED CT license.

3 SOLUTIONS

While European Patient Summary Guidelines do exist, only a small portion of the EU member countries are able to provide such a summary. An even greater issue is the accessibility of these datasets in an international context. The T.I.M.E. (Timely Information Exchange in Medical Emergency) project consortium led by the University-Hospital Muenster has implemented a prototype to show how an international data exchange could be made possible. (TIME, 2019)

3.1 Electronic Medical Records

One prerequisite is the availability of medical data in an electronic format. The T.I.M.E.-project used the German Medical Emergency Dataset (MED), which will be implemented in Germany in 2019. However, in theory each national Emergency Dataset could be used.

The data was stored in a personal electronic patient record (EPR) which could be accessed online. This was necessary since the MED is only stored locally on the German electronic health card, which cannot be read outside of Germany.

3.2 Standardization / Data Exchange

While a European Patient Summary does exist, not all countries follow the according guidelines. From a user perspective, rather than the data format, the data content is important. When a physician accesses an international patient emergency dataset, how can he be sure, that this dataset is in accordance to the European Guidelines and created by a healthcare professional? This becomes even more important with the occurrence of commercial emergency datasets, such as the dataset included in the Apple iOS Health App.

One possibility to solve this issue would be the certification of emergency datasets. Besides the completeness of the data items, an important point is the creation of such a dataset by a medical professional. If such a certification would exist, each international physician would be able to see if the dataset he faces was created according to given standards. These standards could also be created by an international medical association such as the European Society for Emergency Medicine or the International Federation for Emergency Medicine.

3.3 Accessibility and Security

In order to access the emergency data of an international patient, the attending physician must have some key. This key could be a QR-code with a time-limited validity which provides a link to the centrally stored emergency data. As already mentioned, such a single key could be used by anyone who has access to it while the key is valid. If this is not wanted by the patient, a second factor of authentication could be used. This could be for example a code that could be entered by an accompanying person. Another possibility – especially since an accompanying person will not always be available in an emergency – would be a second authentication that must be entered by a medical call centre in the home country after it has assured that the inquiring person is a healthcare professional treating the patient. These call centres could be provided by travel insurance companies.

3.4 Understandability

Since it will not be possible to create a medical emergency dataset which can be understood by any international physician, a translation of this dataset may be necessary. Such translation services do already exist for international patients and can offer a fast translation of the data when needed.

It seems doubtful that the usage of coding systems such as SNOMED will solve the natural language problem. We analysed the emergency datasets of 64 patients which included 476 diagnoses. 18.5% of these diagnoses were not coded (ICD-10) at all, from the remaining coded diagnoses, the ICD-10 coded included less or different information compared to the free text information in 19.8% of all coded diagnoses. Thus – relying only on ICD-10 – in 34.6% of all documented diagnoses information was missing. (Juhra 2015)

4 CONCLUSIONS

Despite the current barriers, it is possible to exchange medical emergency data across borders. However, these data must exist in an electronic format in the home country. With an increasing number of tourists, the number of medical emergencies will rise in this group and a cross-national information exchange of relevant medical data in case of emergency will become more and more important.

So far, the discussion about medical emergency datasets has a very strong technical focus. With already existing guidelines, national implementations and technology, it is time that two countries start the exchange of medical emergency data and help others learn from their experiences, not only from the technical, but also from the medical ones.

The authors strongly suggest to shift the focus of the discussion away from a technical perspective and to concentrate more on the users, the patients and healthcare professionals who will benefit in the end.

ACKNOWLEDGEMENTS

The T.I.M.E. project was funded by the European Union and the Ministry of Labor, Health and Social Affairs (MAGS) of North-Rhine Westphalia as part of the EFRE.NRW program.

REFERENCES

- Born, J., Albert, J., Butz, N., Loos, S., Schenkel, J, Gipp, C., Juhra, C., 2015. The Emergency Data Set for the German Electronic Health Card - Which Benefits Can Be Expected? *Studies in Health Technology and Informatics*, 212, 206-10.
- Born, J., Albert, J., Borycki, EM., Butz, N., Ho, K., Koczerginski, J., Kushniruk, AW., Schenkel, J., Juhra,

- C., 2016. Emergency Data Management – Overcoming (Information) Borders. *Studies in Health Technology and Informatics*, 231, 18-22.
- epSOS, 2014. *Cross-border health project epSOS: What has it achieved?* (online) Available at: <https://ec.europa.eu/digital-single-market/en/news/cross-border-health-project-epsos-what-has-it-achieved> (Accessed 15 Jan. 2019).
- IATA, 2018. *Industry Statistics Fact Sheet*. (pdf) Available at: https://www.iata.org/pressroom/facts_figures/fact_sheets/Documents/fact-sheet-industry-facts.pdf (Accessed 15 Jan. 2019)
- JaseHN, 2019. *JASEHN – Joint Action to Support the eHealth Network*. (online) Available at: <http://jasehn.eu/> (Accessed 15 Jan. 2019).
- Juhra, C., Schenkel, J., Albert, J., Butz, N., Born, J., 2015. In Case of Emergency – Are ICD-10 Codes Enough? *Studies in Health Technology and Informatics*, 208, 195-199.
- SNOMED International, 2019. *5-Step Briefing*. (online) Available at: <http://www.snomed.org/snomed-ct/five-step-briefing> (Accessed 15 Jan. 2019).
- Shapiro, J. S., Kannry, J., Kushniruk, A. W., Kuperman, G., & The New York Clinical Information Exchange (NYCLIX) Clinical Advisory Subcommittee, 2007. Emergency Physicians' Perceptions of Health Information Exchange. *Journal of the American Medical Informatics Association*, 14(6), 700-705.
- Stiell, A., Forster, A. J., Stiell, I. G., & van Walraven, C., 2003. Prevalence of information gaps in the emergency department and the effect on patient outcomes. *Canadian Medical Association Journal*, 169(10), 1023-1028.
- TIME, 2019. *Forschungsprojekte der Stabsstelle Telemedizin - Telemedizinische Informationen bei Medizinischen Notfällen (T.I.M.E.)*. (online) Available at: <https://www.ukm.de/index.php?id=telemedizin-forschung> (Accessed 15 Jan. 2019).