An Overview of Myocardial Infarction Registries and Results from the Hungarian Myocardial Infarction Registry

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Abstract. Nowadays, several databases store information about patients and diseases, but only a few exists that focus directly on myocardial events and treatments. This paper is divided into two parts. In the first part, we list and summarize the ongoing European myocardial projects (Myocardial Ischaemia National Audit Project (MINAP) in England, Swedish Web-system for Enhancement and Development of Evidence-based care in Heart disease Evaluated According to Recommended Therapies (SWEDEHEART) in Sweden, National Registry of Acute Myocardial Infarction in Switzerland (AMIS Plus) in Switzerland). Where possible, we discuss the validity and accuracy of the stored data. In the second part, we introduce the history and legal environment of the Hungarian Myocardial Infarction Registry (HUMIR), and some research results that were achieved with the help of the information in the Hungarian registry.

Keywords. ACS, Infarction registry, Myocardial infarction, Hungarian Myocardial Infarction Registry

1. Introduction

In the recent decades a decline is seen in coronary heart disease mortality [1]. Researches found that there is a difference in the decline based on the socioeconomic background of the patients [2][3]. For instance, the group of less educated people shows a smaller decrement. On one hand, the decline in coronary heart disease mortality can be one of the major significance of public health and a result of the new methods of treatment. On the other hand, more accurate and more complete information is needed to confirm such statements – because cardiovascular disease continues to be one of the most common cause of death in both men and women.

US surgeon Dr. Ernest Amory Codman said: "Every hospital should follow every patient it treats long enough to determine whether or not the treatment was successful and to inquire 'if not, why not?' with a view to preventing similar failures in future." [4]

Nowadays, most of the countries have their own mortality and disease statistics based on International Classification of Diseases – however, these statistics never con-

tain clinical informations, for example results of former examinations, comorbidity or smoking behavior of the patients.

Today only a few system exists that focuses directly on myocardial events and treatments. The common vision behind such registries is the more specific the information we collect, the better quality control we can have. Thus, the quality of the treatment and then the prognosis of the patients improve.

First, the paper lists and summarizes three ongoing European myocardial projects: Myocardial Ischaemia National Audit Project (MINAP) in England, Swedish Web-system for Enhancement and Development of Evidence-based care in Heart disease Evaluated According to Recommended Therapies (SWEDEHEART) and National Registry of Acute Myocardial Infarction in Switzerland (AMIS Plus). Then the authors introduce the history and legal environment of the Hungarian Myocardial Infarction Registry (HU-MIR). Where possible, the authors discuss the validity and accuracy of the registers and some results based on them. Finally, some conclusive remarks are provided.

2. Existing myocardial infarction registers

In this section, we list three ongoing European myocardial projects.

2.1. Myocardial Ischaemia National Audit Project

The Myocardial Ischaemia National Audit Project is a national clinical audit of the management of heart attack in England, Wales and Northern Ireland. It is one of six national cardiac clinical audits that are managed by the National Institute for Cardiovascular Outcomes Research (NICOR), which is part of the Institute for Cardiovascular Science at University College London. MINAP was established in 1999 and data collection began in October 2000.

The aims of MINAP: to audit the quality of care of patients with acute coronary syndrome (ACS) and provide a resource for academic research [6].

Based on the 2015 Annual Report [5] 217 acute hospitals in England, Wales and Northern Ireland participate in the project and continuously send the encrypted data of 130 fields covering demographic factors, co-morbid conditions and treatment specifications in hospital.

80% of hospitals use MINAP software to enter the data into the system and the rest of the hospitals use a locally developed software or commercial applications for this purpose.

The data itself is available for research by application to NICOR.

2.2. Swedish Web-system for Enhancement and Development of Evidence-based care in Heart disease Evaluated According to Recommended Therapies (SWEDEHEART)

SWEDEHEART was launched in 2009 after merging four Swedish national registries on coronary artery disease. The project is supported by the Swedish Society of Cardiology, the Swedish Society of Thoracic Radiology, the Swedish Society of Thoracic Surgery, and the Swedish Heart Association. The registry is financed by the Swedish Association of Local Authorities and Regions, the Swedish state, and the Swedish Heart-Lung Foundation [8].

The primary purpose of SWEDEHEART is to support development of evidence-based therapies in acute and chronic coronary artery disease and in catheter-based or surgical valve intervention by providing continuous information on patient care needs, treatments, and treatment outcomes.

The number of participating Swedish hospitals is 74 in 2016, corresponding to 95% degree of coverage at hospital level. About the data fields [9]:

1. 106 variables for patients with ACS,
2. 75 variables regarding secondary prevention after 12-24 months,
3. 150 variables for patients undergoing coronary angiography/angioplasty and
4. 100 variables for patients undergoing heart surgery.

All data are registered on a web-based interface directly by the caregiver. The data itself is available for research by application to the SWEDEHEART steering group.

2.3. National Registry of Acute Myocardial Infarction in Switzerland (AMIS Plus)

The Swiss registry of acute coronary syndrome is called National Registry of Acute Myocardial Infarction in Switzerland (AMIS Plus). In the list of the aims of the registry, we find:

1. to understand the transfer, use and practicability of knowledge gained from randomised trials
2. to generate input for subsequent prospective and randomised studies.
3. to determine how adherence to guideline-based treatments in the "real world" works.

The AMIS Project was initiated in 1997 [10]. AMIS Plus has been continuously collecting data since then on patients admitted to Swiss hospitals with acute coronary syndromes. Today it operates as an industry-sponsored project. The treating doctor or trained study nurse enter the information online or through a paper-based questionnaire. Out of 106 hospitals treating ACS in Switzerland, 76 hospitals temporarily or continuously send data into the registry (coverage of 72%).

The data itself is available for research with the approval of the AMIS Plus Steering Committee.

2.4. Auditing & Quality of data

One of the key questions about this large amount of data is its accuracy. All of the registers use solutions based on some kind of randomisation technique to check and improve the quality.

MINAP has a specially designed data validation tool. Every year, the system requires every hospital to re-enter 20 data items from the medical records of 20 randomly selected patients [6]. Then, this re-entered data gets compared with the original ones and an agreement score is generated to every hospital. At the end of the process, the hospitals get their scores with advices how to improve performance. The median level of agreement between MINAP data and re-audit data (across all hospitals) was 72% in 2003 and has risen to 89.5% in 2008 [7].

SWEDEHEART uses personal validation solution. A monitor visits approximately 20 hospitals every year. In 2007, accuracy of 96% was reported [9].

AMIS Plus also uses random selection for auditing. Two large and three small hospitals, and about 5-10 patients are randomly selected each year. A summary from 2014 [11] reports there were 0.05% critical, another 0.05% major, and 2.2% minor findings.

3. Hungarian Myocardial Infarction Registry (HUMIR)

In this section, we introduce the Hungarian registry; review the changing of the legal environment; show the completeness and validity, and, finally, overview some research results that were obtained using the data collected.

3.1. History

In the 1970s, World Health Organization (WHO) started a global investigation on acute myocardial infarction registries [12]. Hungary participated in the project with the South Pest Myocardial Infarction Registry [13], which was a paper-based system covering all patients who had acute myocardial infarction (AMI) in six districts of Budapest (affected 373 269 inhabitants [14]). The program made it possible to measure the incidence rates of AMI and the pre-hospital, in-hospital and 1-year mortality rates [15].

Based on the monitoring system, a new patient care system called Myocardial Infarction Patients' Care in CCU also started. The results were published almost a decade later [16]. The improvement on survival is significant, as shown in Table 1.

Table 1.: Mortality rates in 1971 and 1979 in South Pest

	Results - 1971	Results - 1979
Admitted to Coronary Care Unit	7,8%	57,1%
Pre-hospital mortality	30,5%	25,1%
28-day-mortality - Pre- and in-hospital cases	51,7%	41,5%

In the next decades the diagnostic criterias, the clinical forms, and the optimal care strategies have significantly changed the physicians' knowledge about AMI. In addition, physicians faced some other challenges as well:

1. the current International Statistical Classification of Diseases and Related Health Problems (ICD-10) does not separate the two clinical forms of AMI: ST-segment (STEMI) and Non–ST-segment elevation myocardial infarction (NSTEMI)
2. therefore, the hospital and finance databases are not capable to investigate the treatment of AMI
3. the frequency of catheter-directed therapy of STEMI is not known
4. the 28-day and 1-year mortality information is not available
5. the frequency of drugs in the secundary prevention is also not known

As a consequence of the all these deficiencies, a need for a new infarction registry system arose. In January 1, 2010, a web-based system was introduced to collect AMI information from five districts of Budapest and the county of Szabolcs-Szatmár-Bereg [17].

3.2. Legal background

Until 2013, the transfer of the data was voluntary for the hospitals and was based on the patients' full, written informed consent. In Januar 1, 2014 a new legal environment changed this situation. As Hungarian Gazette writes [18], "Diagnosing a myocardial infarction, the patient care doctor is forwarding the patient's identity and healthcare data, concerning the myocardial infarction, to the National Registry of Myocardial Infarction".

Table 2 summaries the essential stages of the Hungarian registry.

Table 2.: Essential stages of the Hungarian Myocardial Infarction Registry

Stage	Data transfer	Date
Research plan		08.07.01 - 09.12.31
IR Pilot Investigation	voluntary	10.01.01 - 11.12.31
HUMIR	voluntary	12.01.01 - 13.02.28
HUMIR	obligatory	13.03.01 - 13.12.31
HUMIR	legal regulations	14.01.01 - present

At April of 2017, the 91 participating hospitals reported 72 281 cases with 67 486 patients.

3.3. Changing of completeness and validity of data in HUMIR from 2011 to 2016

Table 3 contains the number of patients registered in HUMIR and the completeness of the stored data. Completeness is a ratio and calculated on the proportion of two numbers: the numbers of patients treated with AMI originated from National Health Insurance Fund of Hungary (the central official organ of health insurance, supervised by the Government of Hungary; Hungarian acronym: OEP); and the numbers of patients in HUMIR.

Table 3.: Completeness of the registered data in HUMIR

Year	Nr. of Patients (HUMIR)	Completeness of data (HUMIR)
2010	2407	below 30% (voluntary period)
2011	6877	below 30% (voluntary period)
2012	7550	appr. 30% (voluntary period)
2013	7828	51%
2014	10458	67%
2015	12536	82%
2016	13843	83,9%

3.4. Researches and results based on HUMIR

In the last few years, the data of HUMIR has been used in several researches to extract new results. Here we list a few examples.

A research reported that between 1st of January 2010 and 1st of May 2011 4293 patients were registered, among them 52.1% with STEMI, 42.1% with NSTEMI, while 3% of the patients had unstable angina (a type of acute coronary syndrome), and 2.8% of the cases had other diagnosis or the hospital diagnosis was missing [19].

In the year of 2010 and 2011, 4981 patients (3038 men) were included in the database. The target of the research [20] was to compare the clinical data and prognosis of patients with STEMI in that years. Women were significantly older (67.7 ± 13.5 vs. 60.5 ± 12.5 years; $p<0.001$). Hypertension, diabetes, and stroke were more frequent among women, whereas smoking and previous myocardial infarction were found more often among men. Percutaneous coronary intervention was significantly more frequently performed in men than in women (82.4% vs. 75.3%; $p<0.001$).

Based on the data of 8582 myocardial infarction patients (4981 with STEMI), a research found that the hospital, 30-day and 1-year mortality of patients with STEMI were 3.7%, 9.5% and 16.5%, respectively. In patients with NSTEMI these figures were 4%, 9.8% and 21.7%, respectively [21].

Another research based on information stored in HUMIR found that the mean age of STEMI patients was lower by 5.3 years than that of patients treated for NSTEMI. In the group of NSTEMI patients, the occurrence of diabetes, hypertension, peripheral vascular disease, and previous history of myocardial infarction and stroke were significantly more frequent. The in-hospital mortality rate of STEMI patients was 3.7%, and 30-day and 1-year mortality rates were 9.5 and 16.5%, respectively [22].

For 10 000 residents the incidence of myocardial infarction in Budapest was 28.63 in males and 16.21 in females, while in Szabolcs-Szatmár-Bereg county the mean incidence was 32.49 for males and 18.59 for females [23].

A research compared casemix, treatments and outcome for STEMI patients who are treated in Hungary or Sweden [24]. The Swedish data source was the SWEDEHEART registry. There were substantial differences in baseline characteristics between the two countries, with the Hungarian STEMI patients being younger and having more cardiovascular risk factors. More patients in Sweden received thrombolysis (5.4% versus 1.5%) or underwent primary PCI/subsequent coronary angiogram (91.2% versus 84.2%). The 30-day mortality was lower in Sweden than in Hungary (7.9% versus 9.5%; odds ratio 0.81, 95% confidence interval 0.72 to 0.93).

The aim of authors of another research was to obtain data on the significance of the culprit vessel in patients with STEMI treated successfully by primary percutaneous coronary intervention [25]. The culprit vessels were the left main artery, left anterior descendent artery, left circumflex artery, and right coronary artery. The majority of the culprit lesions were found in the left anterior descendent artery (44.3%), the right coronary artery (40.9%), and the left circumflex artery (13.7%). The culprit vessel was overall a highly significant ($p<0.0001$) factor of survival.

In a research [26], the frequency of the real-life usage of coronary intervention, its long-term efficacy and safety in elderly patients with AMI were investigated. A total of 8485 consecutive patients were enrolled; 65% of the patients were male (mean age was 65.1 ± 12.4); and 51% of all cases was STEMI. As a conclusion, the authors state that coronary intervention is underused among the elderly despite the mortality benefit.

In 2015, 12 681 patients had 12 941 acute myocardial infarctions. A research [27] in 2017 found that less than half of patients (44.4%) were treated with STEMI. 91.6% of the patients were treated in hospital with invasive facilities. Most of the patients (94%) with positive coronary arteriography were treated with percutaneous coronary intervention. The 30 day mortality of the whole group was 12.8% vs. 8.6% of patients treated with an invasive procedure.

4. Data mining in cardiology

Early predication using data mining and ECG signal analysis has been proven to be effective in predicting from the feature analysis of these signals myocardial infractions. These have evidently investigated and reported in scientific journals.

For example [28] could predict earlier prediction of heart attack from the non-linear analysis of heart rate variability features.

Deep learning also is used in [29] to provide automated detection of Arrhythmias based on different intervals of Tachycardia ECG. The reported analysis in [29] shows high prediction and accuracy in such analysis.

The classification for myocardial infarction registries could be automated based on characterization of myocardial infarction by decomposition of ECG signals [30] that can be enhanced using deep learning for automated detection of myocardial infarction [31][32].

Some characteristics of heart congestion using signal analysis of myocardial infarction, and congestive heart failure could provide better automation as reported in [33].

5. Summary and Conclusion

We summarized the ongoing European myocardial registry projects in England, Sweden, Switzerland and Hungary. Then the details of the Hungarian Myocardial Infarction Registry was introduced: its history, legal environment and the changing value of completeness of the stored data. Some research results were quoted to demonstrate the using of information stored in the hungarian system. Finally, recent researches and results connected to myocardial infractions and registries were discussed.

As Dr. Ernest Amory Codman said, every hospital should follow every patient to prevent the recurring failures in future. Today only a few country recognized that – in the case of infarction – myocardial registries are the most accurate way to follow every patient.

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