POLISH HEART JOURNAL

Kardiologia Polska
The Official Peer-reviewed Journal
of the Polish Cardiac Society
since 1957

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ISSN 0022–9032
e-ISSN 1897–4279

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Article type: Short communication

Received: December 30, 2024

Accepted: February 5, 2025

Early publication date: February 26, 2025

Rationale and design of the administrative data and electronic medical records-based registry: The Cardiology Scientific Network of the Medical University of Silesia (CardioSilesia)

Short title: Rationale and design of the CardioSilesia registry

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INTRODUCTION

Medical registries are an important source of data on disease occurrence, prevalence and prognosis, healthcare costs, temporal trends, and current approaches, as well as real-life treatment efficacy [1]. These data may help improve risk stratification, healthcare quality, and economics [1]. However, most of the largest medical registries are based exclusively on administrative data [2]. Although utilizing these already existing and readily available large datasets for research appears appealing, there are some drawbacks to such an approach, associated with, among others, incomplete reporting, imprecise International Classification of Diseases (ICD) coding, and frequent missingness of clinically relevant data, including laboratory and imaging findings [3].

There are currently a few ongoing, large, prospective registries in the cardiology field in Poland, but those are either disease- or procedure-specific or based solely on administrative data [2, 4, 5]. A registry encompassing a wide spectrum of patients with cardiovascular disorders and containing detailed information on comorbidities, disease treatment, and outcomes has been missing.

The aim of the paper was to provide the rationale and design of the newly established Cardiology Scientific Network of the Medical University of Silesia (CardioSilesia), the large registry of consecutive patients with cardiovascular disorders treated at high-volume tertiary cardiovascular centers utilizing innovative data extraction and merging approach.

METHODS

The Cardiology Scientific Network of the Medical University of Silesia (CardioSilesia) is an all-comer registry of patients with cardiovascular disease established in 2024. The registry consists of two parts: retrospective, from 2001 to the end of 2023, and prospective, thereafter. The scope of data gathered prospectively is the same as in the retrospective phase, and there is no anticipated time of completion of the registry. Consecutive patients admitted to any of the thirteen cardiology, cardiac and vascular surgery, or intensive care departments of two high-volume tertiary referral centers of the Medical University of Silesia in Katowice (Silesian Center for Heart Diseases in Zabrze, Upper Silesian Medical Center in Katowice) are enrolled. The full list of participating sites is provided in Supplementary material, *Table S1*.

The Cardiology Scientific Network of the Medical University of Silesia is a medical registry utilizing mixed administrative- and medical records-based data. All the patients’ data gathered in electronic medical records in the hospital system (Asseco Medical Management Solutions, Asseco, Rzeszów, Poland) after pseudonymization undergo the ETL (extract, transform, load) process at the Department for Science, Education and New Medical Technologies of Silesian Center for Heart Disease. It includes, among others, the automated transformation of free text (e.g., diagnostic imaging reports) into quantitative or qualitative variables and checking for duplicates and logical errors. While establishing CardioSilesia, the database contained 830 variables, including demographics, diagnosis, comorbidities, imaging and laboratory findings, diagnostic and therapeutic procedures, medical treatment during hospitalization, prescribed therapy at discharge, and medical claims.

The records are further merged with the Silesian Cardiovascular Database, the administrative data registry of the Regional Department of the National Health Fund in Poland (the details have been described previously [2]). The Silesian Cardiovascular Database data adds information on readmissions and their causes (based on ICD-10 codes), ambulatory care visits, diagnostic and therapeutic procedures (based on ICD-9 codes), medical claims, and all-cause deaths at follow-up. The workflow of CardioSilesia is shown in Figure 1.

All the participants signed informed consent forms on admission for anonymized data use for research purposes. Approval for research was waived by the Bioethics Committee of the Medical University of Silesia, given the observational nature of the study.

There was no prespecified statistical analysis plan for the CardioSilesia registry. For the presented study, only descriptive statistics have been performed using R (R Core Team [2022]. R: A language and environment for statistical computing. R Foundation for Statistical Computing, Vienna, Austria).

RESULTS AND DISCUSSION

Between 2001 and 2023, there were 498 293 hospital admissions to the departments participating in the CardioSilesia registry (including 25 453 admissions in the latest year), and those patients were retrospectively included. Most of the patients were admitted to the general cardiology (n = 339 038; 68.0%), and cardiac surgery (n = 76 328; 15.3%). The most frequent cause of admission was chronic coronary syndrome (n = 103 735; 20.8%), which was followed by unstable angina (n = 74 098; 14.9%) and heart failure (n = 54 396; 10.9%). All the primary diagnoses at the admission are presented in Supplementary material, *Table S2*.

To the best of our knowledge, the newly established CardioSilesia is the largest registry of consecutive patients with cardiovascular disease in Poland, utilizing both administrative and medical records-based data. When established, it contained retrospectively collected data on almost half of a million hospital admissions, with expected further enrollment of about twenty-five thousand patients per year. It utilizes automated data extraction algorithms based on free text search.

There are several ongoing prospective cardiovascular registries in Poland that are focused on specific diseases, populations, or interventions. Among them, one of the largest registries of patients presenting with acute coronary syndrome in Europe, the nationwide PL-ACS (Polish Registry of Acute Coronary Syndrome), has enrolled more than 700 000 patients and provided valuable data on the treatment and outcomes of patients with ACS in Poland throughout the years [4]. Other registries, such as ORPKI (Polish National Percutaneous Coronary Interventions Registry), endorsed by the Association of Cardiovascular Interventions of the Polish Cardiac Society (PCS), KROK (Polish National Registry of Cardiac Surgical Procedures), which was the initiative of the Club of Polish Cardiac Surgeons, and POL-TAVI (Polish Registry of Transcatheter Aortic Valve Implantation) are the excellent source of information on the current percutaneous and surgical treatment of cardiovascular disease in Poland [5–7]. Finally, the Scientific Platform of the PCS and the Scientific Platform of the "Club 30" of the PCS, established recently, became an effective tool to enable the initiation of and participation in multicenter studies by facilitating the establishment of multicenter cooperation and providing electronic case report forms. It resulted in the initiation of multiple smaller but timely registries of specific cardiovascular disease cohorts, addressing relevant aspects of epidemiology, treatment, and prognosis [8].

Despite the abundance of data from observational cohort studies on specific cardiovascular conditions or treatments, there is a paucity of information on the general cardiovascular disease population in Poland. In patients with cardiovascular disease, the presence of other cardiovascular comorbid conditions is highly prevalent [2]. However, the mutual interactions of coexisting cardiovascular disorders and their impact on adherence to guideline-recommended treatment and prognosis are rarely investigated. These aspects may not be fully addressed using datasets focused on patients with one specific diagnosis. Moreover, administrative data, most often used in studies assessing the unselected cardiovascular population, may not accurately determine comorbidity [3]. The CardioSilesia registry, which includes a contemporary cohort of unselected patients with cardiovascular disease and utilizes various data sources (electronic medical records and administrative data), has been established to address this issue.

Key benefits and potential applications of this registry are as follows: 1) real-life validation and assessment of the applicability of the results of key clinical trials within the Polish healthcare system, 2) assessment of the quality of care based on the established indices (e.g., first medical contact-to-balloon time in ST-elevation myocardial infarction, utilization of cardiac rehabilitation programs after ACS), 3) platform for cost-effectiveness analysis of new therapies, 4) pragmatic, registry-based clinical trials (similar to SWEDEHEART registry [9]), 5) gathering of preliminary pilot data to verify hypotheses to be tested in large randomized trials, 6) accumulation of data for machine learning.

In conclusion, CardioSilesia is a newly established registry of unselected patients with cardiovascular disease treated at high-volume tertiary referral centers in Poland. The large sample size and wide spectrum of collected data, including past medical history, comorbidities, medical treatment, laboratory tests, diagnostic imaging, and invasive procedures performed in those patients, will allow us to evaluate the treatment approaches and outcomes as well as factors influencing prognosis in this contemporary cohort of patients.

Supplementary material

Supplementary material is available at https://journals.viamedica.pl/polish_heart_journal.

Article information

Acknowledgments: We would like to express our sincere gratitude to Professor Tomasz Szczepański, MD, PhD, Rector of the Medical University of Silesia, for the inspiration, support, and guidance in establishing the CardioSilesia registry.

Conflict of interest: None declared.

Funding: None.

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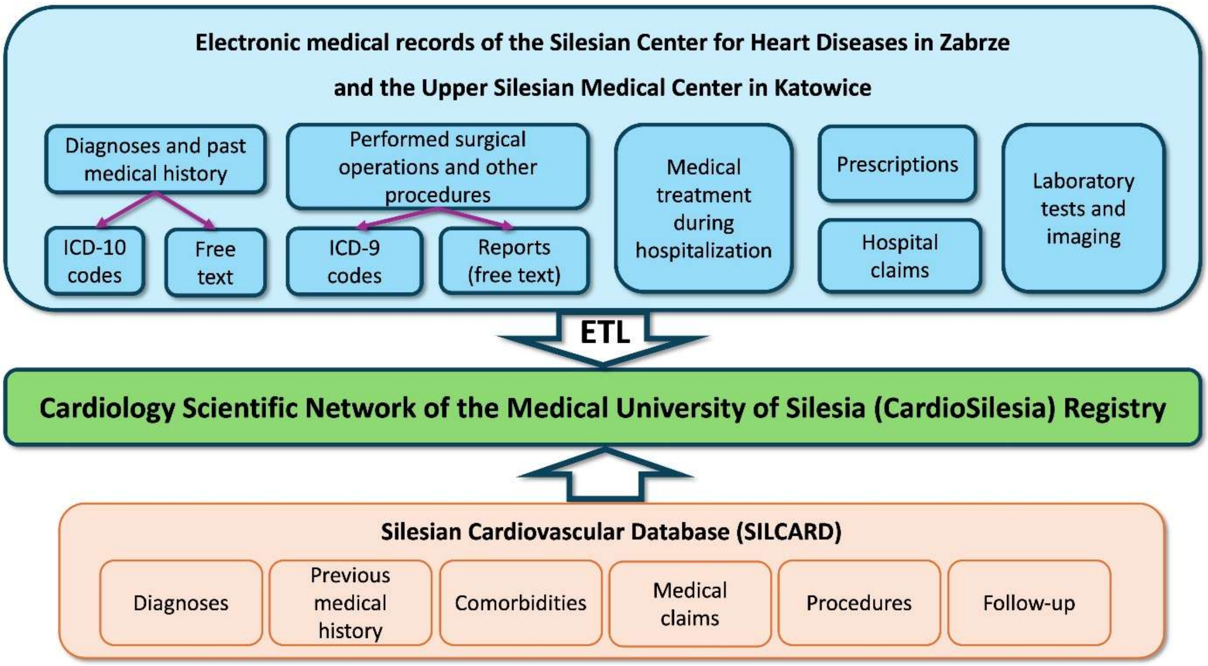

Figure 1. The design and workflow of the CardioSilesia registry

Abbreviations: ETL, extract, transform, and load