

Cardiovascular registries – bibliometric analysis of structure and characteristics

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Abstract

Clinical registries play an increasingly important role in determining national health policy, financial effectiveness, and generating scientific hypotheses. However, there is no universally accepted structure for these registries in Europe or worldwide. Many countries face significant challenges in organizing their clinical registries, considering the local peculiarities of the healthcare system, political organization, financial constraints, and labor capabilities. When organizing a national registry, it is essential to find the right balance between available resources, structure, and the benefits obtained—whether scientific, financial, or related to local health policy. A possible, but incomplete, quantitative assessment of the scientific usefulness of a registry can be determined through bibliometric analysis, which examines the number of unique published articles containing scientific analyses based on the respective registry.

Our study aims to analyze the correlation between various registry characteristics and the scientific value of 16 national coronary registries in Europe (plus the USA), examining the number of unique published articles in PubMed.

Keywords

clinical registry, invasive cardiology, registry structure, bibliometric analysis

Introduction

Over the past 30 years, there has been expansive growth in the range and number of clinical registries. For the purposes of our analysis, a coronary registry was defined as a dedicated multicentre database systematically collecting information on clinical and procedural details of patients undergoing diagnostic angiography and coronary intervention or coronary intervention only (Lazem and Sheikhtaheri 2022). Coronary registries can be used to inform health policy, improve the quality and cost-

effectiveness of patient care, allow for access to data for clinical research, and assist in monitoring the uptake and safety of novel treatments and procedures (Dawson et al. 2021). Data management practices and registry purposes are highly varied. There is no universally accepted structure for cardiovascular registries in Europe and worldwide (Dawson et al. 2021). However, many countries have serious problems organizing clinical registries, potentially due to concerns about costs and a lack of a clearly defined utility and value. In many countries, there are difficulties in organizing registries due to a lack of

sufficient resources—informational, organizational, financial, workforce, etc. When organizing their own national registry, the question arises of how to organize it, taking into account the local peculiarities of the health-care system, political organization, and financial and labor capabilities. By their nature, clinical registries have an inherent structural contradiction: the larger they are in scope, the more useful they are, but they also require more resources to function, and vice versa. Resources can be financial, organizational, personnel, and others. The primary resource is personnel, as data entry must be carried out by qualified and motivated staff. The more data collected, the more difficult its collection becomes, and with a higher error rate. A smaller amount of collected data makes the registry less valuable for its users. When organizing a national registry, it is necessary to find the proper balance between the registry's structure and the resource capabilities of the respective country, ensuring continuous and sustained functioning.

Determining the value of a registry's operation is quite challenging and can only be partially estimated. The main categories of users of the obtained data ("registry stakeholders") (Institute of medicine Committee 2002) are: clinical specialists/scientists, healthcare managers, governing institutions/health policy, financiers, patients, industry, and media. The lack of published data does not allow for an assessment of the usefulness of a given registry for patients, industry, media, and policymakers. The health policy value of a registry can be indirectly assessed by the level of registry legislation and the extent of government or public funding for this activity at the local level.

A possible but incomplete quantitative assessment of the usefulness can be determined with regard to clinical specialists and scientists who use registry data to publish scientific articles. By using an instrument from bibliometric analysis—examining the number of unique published articles with scientific analyses based on respective registry—one can assess how useful it is at both a national and world level.

The term 'bibliométrie' was first used by Paul Otlet and defined as 'the measurement of all aspects related to the publication and reading of books and documents. (Rousseau 2014). Bibliometrics is based on the enumeration and statistical analysis of scientific output, such as articles, to quantitatively estimate the influence or impact that a selected research article has on future research (Okubo 1997).

Our study aims to analyze the correlation between various characteristics and the value of coronary registries in Europe (and as a gold standard, USA), examining the number of unique published articles.

Our research in the PubMed database demonstrates a lack of articles analyzing the structure of clinical (incl. cardiovascular) registries and comparing them with similar ones in terms of scientific benefit or value using bibliometric analysis.

The aim of this research was to analyze European practice of national coronary registry organization, structure, and function.

Methods

A preliminary list of suitable registries that meet the following criteria was compiled:

- To be national—encompassing all or nearly all interventional centers in the respective European country.
- To be European. For comparison purposes, the American coronary CathPCI Registry was added, as it has the widest scope and largest volume of collected data—serving as a 'gold standard.'
- To be coronary—to include:
 - a. All or the majority of diagnostic investigations AND coronary procedures for any clinical indication in the respective country.
 or
 - b. All or the majority of coronary procedures for any indication in the respective country.
 or
 - c. All or the majority of coronary procedures related to acute myocardial infarction in the respective country.

Information regarding at least some of the aforementioned characteristics of the respective registry should be published in English for comparison purposes.

The registry should have at least one article citation in the PubMed database (<https://pubmed.ncbi.nlm.nih.gov>) related to its data. One exclusion was made: the Bulgarian Coronary Registry, 'BULPCI,' was included for scientific purposes.

The reasons to use the PubMed service are: PubMed delivers a publicly available search interface for MEDLINE, making it the premier source for biomedical literature and one of the most widely accessible resources in the world are. PubMed is accessed for free, with more than 36 million citations for biomedical literature from MEDLINE, life science journals, and online books.

The following criteria were adopted for appropriately citing the obtained results from the respective registry: A keyword search was performed using the full or partial name of the registry, or its abbreviation. Synonyms such as 'registry' or 'survey,' and 'PCI' or 'interventional' were used. A keyword search was performed in the article title, abstract, or keywords section. English versions of registry names were used, in Latin.

Exclusion of some articles necessitated examination of the entire text to determine the context of the registry name's usage. Duplicate article names were excluded from analysis.

Identification of unique articles is as follows: The eligibility criteria for an appropriately cited article citing the respective national registry are:

The scientific knowledge presented in the article should be based on the use and analysis of data, at least some of which are collected from the specific registry.

For each registry, a keyword search was conducted in the medical databases MEDLINE and PubMed, as well as using Google's search functions. All available published

information regarding the given registry was analyzed for the following variables:

National registry name: full name and abbreviation

Country: To facilitate the reading of the text, national registries are identified by the name of the respective country and its Alpha-2 code, with the full names listed in Table 1.

Address: internet address of web platform if found.

Owner/Responsible organisation:

Funding: Presence or absence of financing and method of financing if available.

Number of participating centers: For the purposes of this study, according to the number of centers, the registries are divided into four categories: with < 20 centers, with 20–50 centers, with 51–100 centers, and very large, with > 101 centers.

Types of procedure: types of coronary diagnostic or interventional coronary procedure, for all clinical indications or only for myocardial infarctions.

Year of initiate: Registries are divided into three groups: started before 2000, between 2001–2010, and between 2011–2020.

Registry language: Language of registry web interface OR registry report article.

Working status: Functioning or non-functioning at the time of writing the article.

Participation: Voluntary or mandatory participation in the national registry.

Number of variables: the total number of variables collected in the registry. For the purposes of this study,

registries are classified as small (< 100 variables), medium-sized (101–200 variables), and large (> 201 variables).

Follow-up: Presence or absence of manual or automatic follow-up data collection functionality.

Interface: Web-based only, specific software or other method for data collection.

Quality control: Presence or absence of a mechanism for quality control of data acquisition.

Year reports: Presence/absence of periodic reporting of data collection and analysis.

Number of unique articles: number of unique PubMed articles as described earlier. Registries are classified as follows: those without unique articles, those with a very small number of unique articles (<10), those with a small number (11–50), and those with a large number (>51).

Results

Using the criteria mentioned above, we identified 16 coronary intervention registries in Europe, along with CathPCI from the USA (Moussa et al. 2013); the overall number is 17. The information collected on the specified parameters characterizing each registry is presented in Table 1.

Most variables are quantitative (except number of centers and number of variables), so we used the Chi Square Test to analyze. Due to restrictions on expected cell frequencies, only a histogram presentation of the data was used.

Table 1. Coronary registries, data sources, and some parameters.

National registry name (with abbreviation)	Bibliography	Country	Country Alpha 2 code	Number of centers:	Number of variables:	Citations	Year reports:
CathPCI Registry	(Moussa et al. 2013)	US	US	1577	252	230	n/a
SCAAR Registry	(Jernberg et al. 2010), (SWEDEHEART Group 2017)	Sweden	SE	30	150	186	online annual report
The Myocardial Ischaemia National Audit Project (MINAP)	(Wilkinson et al. 2020), (Herrett et al. 2010), (MINAP)	UK (without Scotland)	UK	230	123	96	online annual report
National Registry of Invasive Cardiology Procedures (ORPKI)	(Kleczyński et al. 2018), (Siudak et al. 2021)	Poland	PL	163	n/a	52	yes
Russian Acute Coronary Syndrome Registry (RusACSR)	(Gridnev et al. 2016), (Popova et al. 2021)	Russian Federation	RU	213	>70	4+*	yes
Hungarian Myocardial Infarction registry (HUMIR)	(János et al. 2021), (Sinka Lászlóné Adamik et al. 2021)	Hungary	HU	20	178	31	n/a
Spanish Cardiac Catheterization and Coronary Intervention Registry	(Freixa et al. 2022), (Serrador Frutos et al. 2017)	Spain	ES	121	n/a	24	online annual report
Portugal Interventional Registry (RNCI)	(Gomes 2016), (Pereira et al. 2016)	Portugal	PT	25	n/a	4	n/a
SLOVak Register of Acute Coronary Syndromes (SLOVAKS)	(Alberly et al. 2017)	Slovakia	SK	69	n/a	3	n/a
The Estonian Myocardial Infarction Register (EMIR)	(EMIR Registry)	Estonia	EE	20	n/a	2	n/a
Norwegian Registry of Myocardial infarctions (NORMI)	(Govatsmark et al. 2016), (Jortveit et al. 2014)	Norway	NO	48	107	2	n/a
Danish Heart Register (DHR)	(Abildstrøm and Madsen 2011), (Özcan et al. 2016)	Denmark	DK	12	60–70	2	n/a
National Swiss PCI Survey	(Wagener et al. 2022)	Switzerland	CH	39	n/a	1	n/a
Hellenic Heart Registry on Percutaneous Coronary Interventions (HHR-PCI)	(Papaioannou et al. 2014)	Greece	GR	18	n/a	1	no
French National Register Coronary Angiograms and Coronary Angioplasties (France PCI)	(France PCI), (Rangé et al. 2023)	France	FR	61	150	19	online annual report
Austrian National Cathlab Registry (ANCALAR)	(Mühlberger et al. 2020), (Mühlberger et al. 2021)	Austria	AT	36	90	2	yes
Bulgarian Coronary Registry (BULPCI)	(Mateev and Sidjimova 2019)	Bulgaria	BG	59	65	0	yes

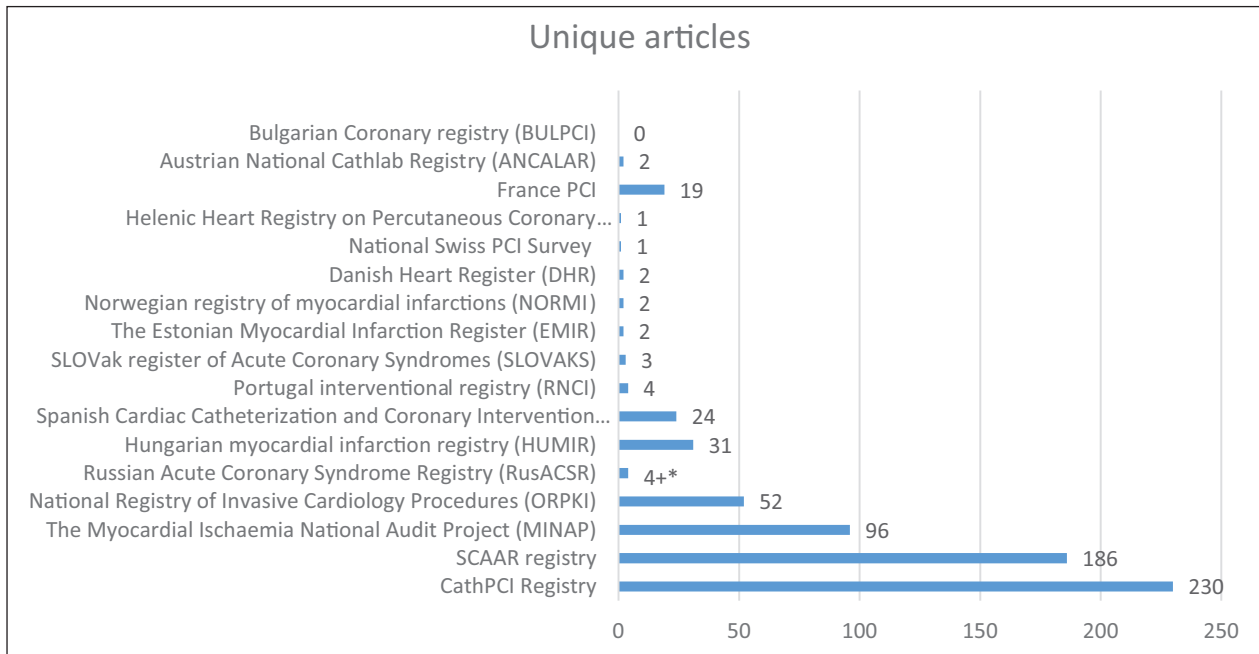


Figure 1. National coronary registries and number of PubMed unique articles. * - RusACSR: we found a large number of articles published in the own scientific data system, the Russian Science Citation Index (RSCI) (RSCI 2024)—more than 2300 articles in Russian are cited. The number of unique articles is unknown.

The number of unique articles for coronary registries is reported in Fig. 1.

Unique articles: Five national registries have more than 50 unique articles (including RU in Russian, US, SE, UK, PL), with four of them being large with over 160 centers. The only exception is Sweden, with 30 centers. The Swedish SCAAR registry is the only entirely European registry with more than 150 unique articles published in English. Three of the registries with the most unique articles (RU, SE, PL) have voluntary data collection, while data collection is mandatory only in the UK and US (in the US, mandatory for coronary interventions and voluntary for diagnostics). Three out of the five (UK, US, SK) most cited registries have a direct connection to databases.

Funding: Data mining results (Table 2) show that only four registries (23.5%) have published data on sources of funding, two centers (11.8%) declared no funding, and for 11 national registries (64.7%), there is a lack of published data on the type of funding. One national registry is funded solely by the government (RU), while others have mixed funding, including local budgets (from local healthcare providers), government funding, and support from local hospitals. The distribution of funding status and citation was presented in Table 3, with statistical significance be-

tween funding status and citation ($p = 0.153$). Registries without funding do not function. (Table 2.)

All registries with over 100 citations in Europe have documented funding.

Data on the number of centers involved in data collection (Table 4) is approximate, as the numbers are reported for different years and can change from year to year. The number of centers provides an approximate estimate of the organizational scale, ranging from 12 to 1,577. Small countries with fewer than 20 centers include two; medium-sized countries with 20–50 centers include seven; large countries with 51–100 centers include three; and very large countries with more than 101 centers include five. Sweden (SE) has a very large number of citations (>180). Data analysis showed a statistically significant correlation between the number of centers and the number of unique articles, with $p = 0.049$.

Regarding the distribution of indications for data collection, the registries are as follows: Three registries focus on coronary interventions for any clinical indication, five registries focus on coronary interventions only for myocardial infarctions, and nine registries cover both coronary diagnostic and interventional procedures. No

Table 2. Coronary registries, their funding, and current status.

National registry name	Funding	Working status
SCAAR Registry	Mixed: local budgets (local healthcare provider) and hospitals	working
The Myocardial Ischaemia National Audit Project (MINAP)	Government (NHS) and hospitals	working
Russian Acute Coronary Syndrome Registry (RusACSR)	Government	working
Danish Heart Register (DHR)	Local regional budgets	working
Helenic Heart Registry on Percutaneous Coronary Interventions (HHR-PCI)	No	stopped
Bulgarian Coronary Registry (BULPCI)	No	stopped

Table 3. National registries, their funding, and unique articles.

National registry name	Funding	Unique articles
Russian Acute Coronary Syndrome Registry (RusACSR)	Government	4+ *
CathPCI Registry	n/a	230
SCAAR Registry	Mixed	186
The Myocardial Ischaemia National Audit Project (MINAP)	Mixed	96
National Registry of Invasive Cardiology Procedures (ORPKI)	n/a	52
Hungarian Myocardial Infarction Registry (HUMIR)	n/a	31
Spanish Cardiac Catheterization and Coronary Intervention Registry	n/a	24
French National Register Coronary Angiograms and Coronary Angioplasties (France PCI)	n/a	19
Portugal Interventional Registry (RNCI)	n/a	4
SLOVak Register of Acute Coronary Syndromes (SLOVAKS)	n/a	3
The Estonian Myocardial Infarction Register (EMIR)	n/a	2
Norwegian Registry of Myocardial Infarctions (NORMI)	n/a	2
Danish Heart Register (DHR)	Local regional budgets	2
Austrian National Cathlab Registry (ANCALAR)	n/a	2
National Swiss PCI Survey	n/a	1
Helenic Heart Registry on Percutaneous Coronary Interventions (HHR-PCI)	No	1
Bulgarian Coronary Registry (BULPCI)	No	0

Table 4. Number of centers in national registry end unique articles.

Registry name	Number of centers	Unique articles
CathPCI Registry	1577	230
SCAAR Registry	30	186
The Myocardial Ischaemia National Audit Project (MINAP)	230	96
National Registry of Invasive Cardiology Procedures (ORPKI)	163	52
Russian Acute Coronary Syndrome Registry (RusACSR)	213	4+ *
Hungarian Myocardial Infarction Registry (HUMIR)	20	31
Spanish Cardiac Catheterization and Coronary Intervention Registry	121	24
Portugal Interventional Registry (RNCI)	25	4
SLOVak Register of Acute Coronary Syndromes (SLOVAKS)	69	3
The Estonian Myocardial Infarction Register (EMIR)	20	2
Norwegian Registry of Myocardial Infarctions (NORMI)	48	2
Danish Heart Register (DHR)	12	2
National Swiss PCI Survey	39	1
Helenic Heart Registry on Percutaneous Coronary Interventions (HHR-PCI)	18	1
France PCI	61	19
Austrian National Cathlab Registry (ANCALAR)	36	2
Bulgarian Coronary Registry (BULPCI)	59	0

correlation was found between the indication and the number of unique articles.

Five of the registries started before the year 2000; the vast majority were implemented between 2000 and 2010 (eight registries), and four registries began operating after 2011. The duration of operation of the registries does not correlate with their usefulness. Among the five oldest registries (CH, ES, AT, US, SE), two have a high number of unique articles (US and SE), while two have very few articles (CH and AT). In the group of the four most recently

created registries (EE, NO, PL, FR), one has a moderately large number of articles (PL). Two registries, the Greek and Bulgarian registries (documented as not having funding), have ceased operation—Greece after 3 years and Bulgaria after 9 years.

Participation in coronary registries can be either voluntary or mandatory. Eight countries have voluntary participation (three of which have near 100% coverage), while seven countries have mandatory participation. In the US, diagnostic procedures are voluntary, but coronary interventions are mandatory for data collection. The participation status of one registry is unknown (SK). No correlation was found between the type of participation and the number of citations.

The coronary registries differ in the volume of collected data and have significantly varying numbers of variables. For 7 out of 19 centers, the number of variables is unknown. Four centers collect fewer than 100 variables, five centers collect between 100 and 200, and only the US CathPCI registry collects large data with more than 200 variables. The number of variables does not correlate with the value of a given registry, as estimated by the number of articles published.

Four coronary registries are automatically linked to different national databases (US, UK, SE, and DK) and receive data on all-cause mortality. Four registries offer the option for manual follow-up data submission. One center reports a lack of capability for follow-up (RU). Three of the four most-published registries have this option. The Dutch registry has an automatic link with the national database but has a low number of published articles. The process of automatic linking is facilitated by the presence of a universal national identification number, such as the Personal Identification Number (EGN), NHS number, etc.

Regarding the interface of coronary registries, the options are: web-based data collection or specially developed public software to connect to the corresponding database. In Switzerland, a standardized online questionnaire is used with general information and a small list of variables. Three registries (UK, US, and FR) use public vendors to develop software that enhances data collection and links to the registry database. Ten registries have a web interface for data collection.

Three registries are reported not to control data quality (ES, SH, BG), while eight national centers conduct quality control of the collected data through annual audits (RU, DK, AT, FR, SE, UK, US, HU). One registry (NO) relies only on local hospital control. Four out of the five most-published registries (US, UK, RU, and SE) have a quality control system, while data for the fifth one (PL) is missing. In the intermediate group with 10–50 unique articles, there are two registries: one with data quality control (HU) and the other without (ES).

Data analysis of unique articles from two registries (Table 5) with a medium number of publications, between 20 and 50 (HU and ES), reveals that they have practically opposite characteristics. The HU registry has few centers, focuses only on acute myocardial infarctions, started

Table 5. National registries with 20 to 50 published articles and their characteristics.

Registry name	Hungarian myocardial infarction registry (HUMIR)	Spanish Cardiac Catheterization and Coronary Intervention Registry
Number of centers	20	121
Type of procedure	myocardial infarction only	diagnostic procedures and coronary interventions
Year of initiate	2010	1990
Participation	mandatory	voluntary but close to 100%
Number of variables	178	n/a
Interface	web based	web based
Quality control	yes	n
Citations	31	24
Year reports	n/a	online annual report

relatively late in 2010, with mandatory participation and a very large number of variables—178 (the most extensive in Europe, larger than both SE and UK)—and allows for quality control. In contrast, the ES registry includes a large number of centers (121), covers both diagnostic procedures and coronary interventions for all indications, has been operating since 1990, is voluntary but has around 100% coverage, and lacks the possibility of data quality control, although it provides annual activity reports, including in English.

Discussion

Our analysis includes 16 coronary intervention registries in Europe (plus CathPCI from the USA), which significantly differ in structure. We were unable to find any published analysis comparing the structure and usefulness of clinical registries (especially cardiovascular) with our data.

The clinical indications for inclusion in the registries are quite diverse, covering the full spectrum of acute and chronic coronary syndromes. The number of published articles associated with the studied registries varies significantly, ranging from 0 to 230 (over 2,300 in RSCI), with a small group having more than 50 articles and the vast majority having very few.

There is no correlation between the number of participating centers and the number of published articles—there are registries with many centers and many articles, few centers and many articles, as well as few centers and few articles. Regarding the launch of the registry, no clear correlation is observed between the initiation of the registry and its scientific value. Later registries, which were expected to analyze the shortcomings of existing registries and adapt their structure, do not demonstrate more published articles. It can be assumed that when creating new registries, no scientific analysis of the structure of previous registries was conducted to achieve optimal results.

Contrary to the expectation that mandatory registries should contain a greater quantity of more consistent data and thus potentially have greater scientific value, this is not observed. The volume of collected data, based on the number of characteristics, also does not correlate with the scientific value of the registry. As expected, new technologies can influence the scientific value of a registry. A very small number of registries (4 out of 17) are modern enough to support

automatic linkage with other databases, allowing for automatic tracking, which benefits them in terms of the number of published articles. In most cases, the presence of a data quality control system provides an advantage in terms of the number of articles. A user-friendly interface is a feature that requires only an initial investment to create but significantly facilitates data collection and improves data quality.

The remaining analyzed characteristics that determine the structure of the registries include funding, types of participation, clinical scenarios (diagnosis), number of variables collected, presence of quality control, and the number of centers involved. An analysis of the results from the Hungarian (Jánosi et al. 2021), (Sinka Lászlóné Adamik et al. 2021), and Spanish (Freixa et al. 2022), (Serador Frutos et al. 2017) registries suggests that similar results can be achieved with different or opposing combinations of characteristics.

Conclusion

There is no common standard for creating cardiovascular registries in Europe. They vary significantly in structure and characteristics, as well as in scientific value, which is assessed through the number of unique articles published in PubMed. The analysis of the collected data shows that some characteristics are associated with increased scientific value, but the presence of certain characteristics does not guarantee it. Of particular interest are the structure and organization of two registries with a moderately large number of publications: the Hungarian Myocardial Infarction Registry (HUMIR) and the Spanish Cardiac Catheterization and Coronary Intervention Registry. A more in-depth analysis is needed, focusing on these two registries, to assess which characteristics and factors, either individually or in combination, contribute to achieving significant scientific value. The lack of published data on the organization, structure, and functioning of coronary registries represents a significant barrier to studying international experiences.

Creating a functioning registry in invasive cardiology requires an in-depth study of foreign experiences, organizations, and solutions and adapting them to the specific socio-economic, personnel, and organizational conditions of the respective country in order to achieve maximum effect with minimal resources.

Limitations

The proposed analysis has several important limitations. There is a systematic lack of published data on the organization, structure, and functioning of coronary registries, which significantly hinders the analysis. The bibliometric method used to assess the value of clinical registries only considers their scientific usefulness and does not take into account their value for other stakeholders—patients, healthcare managers, health policymakers, the medical industry, the press, etc.

The study of coronary registries in Europe only includes indexed articles in English and cannot capture

citations in individual European languages. A significant portion of the value from the respective registry remains with local users of the information and cannot be assessed by the proposed analysis.

Additional information

Conflict of interest

The authors have declared that no competing interests exist.

Ethical statements

The authors declared that no clinical trials were used in the present study.

The authors declared that no experiments on humans or human tissues were performed for the present study.

The authors declared that no informed consent was obtained from the humans, donors or donors' representatives participating in the study.

The authors declared that no experiments on animals were performed for the present study.

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Author contributions

Hristo Mateev - Conceived and designed the analysis; Collected the data; Contributed data or analysis tools; Performed the analysis; Wrote the paper.

Tzvetomir Dimitrov - Contributed data or analysis tools; Performed the analysis.

Tanya Dimitrova - Contributed data or analysis tools; Performed the analysis.

Anton Koychev - Contributed data or analysis tools; Performed the analysis.

Data availability

All of the data that support the findings of this study are available in the main text.

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