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Abstract

Aims

The quality registry SWEDEHEART covers data across the patient pathway after an acute myocardial infarction (MI), from hospital care to secondary prevention. Although cardiac rehabilitation (CR) is strongly recommended after an MI, there is still heterogeneity regarding standards, uptake, and adherence rates. The aim of the SWEDEHEART-CR registry is to provide continuous information on secondary prevention and CR-performance to support the audit and development of evidence-based practice. To facilitate quality improvement and research initiatives, a description of the characteristics and development of the SWEDEHEART-CR registry is needed.

Methods and results

The SWEDEHEART-CR registry starts with data obtained during hospital care and then collects data at out-patient visits two-months and one-year after discharge, and at start and end of an exercise-based CR programme. The registry data covers comorbidities, biochemistry, blood pressure, anthropometric variables, medication, psychosocial- and lifestyle variables, readmissions, patient-reported outcome measures, attendance in CR-related programmes and physical fitness variables. Over 100.000 patients with MI have been included in the SWEDEHEART-CR registry since its start in 2005. From initially covering 35 centers (47%) and 2200 patients annually (27%), SWEDEHEART-CR has developed to a nation-wide registry with 75 centers (100%) and 8800 patients annually (80%) in 2020.

Conclusion

The SWEDEHEART-CR registry includes a high proportion of the national MI population entering a CR programme and is a powerful tool for quality audit, improvement, and research.

The registry provides insights into the characteristics, treatment, and outcomes of evidence-based secondary preventive practice, ultimately leading to better cardiovascular health.

Keywords: cardiac rehabilitation, cohort, coronary artery disease, myocardial infarction, secondary prevention, quality registry

Introduction

While early mortality for patients with acute myocardial infarction (MI) has declined in recent years there is still a large unmet need for general implementation of effective secondary prevention strategies to further improve long-term prognosis (1, 2). Patients are at high risk for recurrent MI and death during the first years after MI (3), with the risk remaining substantial even beyond five years (4). Cardiovascular risk reduction and the promotion of healthy lifestyles through secondary prevention and comprehensive cardiac rehabilitation (CR) programmes are essential to reduce the risk of recurrent cardiovascular events, all-cause mortality and to improve psychosocial well-being (5-7). Participation in CR has therefore received the highest class of recommendation and level of evidence in European guidelines and should be offered to all patients after MI (8). Core components of a multidisciplinary CR programme are well recognized and should include individual patient assessment, management and control of cardiovascular risk factors, physical activity counselling, prescription of exercise training, dietary advice, psychosocial management, vocational support, and lifestyle behaviour change including patients´ adherence and self-management (9).

Despite strong evidence-based benefits of CR, there are still large variations regarding standards, uptake and adherence across countries, hospitals, and healthcare regions, leading to health inequalities and potentially severe consequences for patients and populations (10, 11). The large Swedish quality registry SWEDEHEART (The Swedish Web-system for Enhancement and Development of Evidence-based care in Heart disease Evaluated According to Recommended Therapies) continuously records and provides on-line information on the quality and content of patient care, treatments, and outcomes after MI (12). The long-term goal is to contribute to reduced mortality and morbidity in patients with cardiac disease, to reduce national inequalities and to improve the cost-effectiveness of patient care. As a result

of the widespread use of SWEDEHEART in clinical settings and large research projects, the management of acute MI in Sweden is in the frontline internationally (13). However, there is still a need to investigate if secondary preventive care can be improved by taking a similar approach. The registry auditing continuous information on secondary prevention and CR-performance after MI is referred to as the SWEDEHEART-CR registry (nationally known as SEPHIA). It is the largest CR-registry in the world and data has been collected since 2005.

To translate evidence into clinical practice, the European Association of Preventive Cardiology (EAPC) has developed an accreditation checklist to define minimal and optimal CR standards and relevant CR quality indicators, to benchmark and improve quality of CR care across Europe (14). A collaboration between national registries to provide a common European CR registry with harmonized and standardized variables should be a prioritized area. The EuroHeart is an international collaboration coordinated by the ESC, which provides common definitions of quality-of-care indicators and the availability of an IT infrastructure across Europe (15). Initially, EuroHeart will support continuous improvement of care and outcomes in the areas of acute coronary syndrome (ACS), percutaneous coronary interventions (PCI), heart failure, valve disease and atrial fibrillation. One option may be to also include relevant CR indicators in the future development of EuroHeart, aiming to support continuous improvement of all aspects of cardiology practice and consequently cardiovascular health, across Europe.

Aim

The aim of the SWEDEHEART-CR registry is to provide continuous information on the secondary prevention provided and CR-performance to support the audit and development of evidence-based practice. To facilitate quality improvement and research initiatives, a detailed description of the characteristics and development of the SWEDEHEART-CR registry is essential.

Funding

The SWEDEHEART registry is mainly financed by the Swedish Association of Local Authorities and Regions and with support from the Swedish Heart-Lung Foundation (Figure 1). Participating hospitals and centers are not reimbursed for entering data into the registry. Using registry data for the participating hospitals is on the other hand free of charge, while researchers pay for the costs of data extraction.

Quality of care interventions

To provide users with direct feedback of the process of care and outcomes, comparisons over time and with other hospitals, interactive reports of selected quality indicators are continuously available on the SWEDEHEART webpage (www.swedeheart.se) (16).
Annual reports are compiled with national, regional and county-based reports using these data, with high media interest in top-ranking centers (11). In these reports, temporal trends for treatments and outcomes are also presented. In Sweden, as well as in other countries, more and more patients are reaching treatment goals for blood pressure and low-density lipoprotein cholesterol (LDL-C), while changes in variables associated with non-pharmacological behavioral changes are less promising (10, 11).
Data presented in the annual reports allow comparisons between centers and include national averages, facilitating benchmarking of performance against national targets. The publicly available data and open discussions around the differences in patient care have promoted quality improvement initiatives which have led to improved adherence to national guidelines (11).
The SWEDEHEART-CR database is an important resource in producing high impact research and the research interest in this area has accelerated during the latest years. The new concept of registry-based randomized controlled trials (RRCT), pioneered by researchers in

SWEDEHEART, is a pragmatic and less selective alternative to classical RCTs. Results from several large RRCTs from SWEDEHEART have been published in the most highly ranked medical journals, influencing the acute care of MI throughout the world (17, 18). One SWEWDEHEART-CR based RRCT, The Remote Exercise Study, is planned to start during 2021. The authors encourage further study applications, as this study design creates unique possibilities to increase the evidence-base of secondary prevention and CR.

Setting

In 2005, when the SWEDEHEART-CR registry was started, 35 centers (47%) reported data to the registry. Early in 2007, this number had already increased to 47 centers (63%). In 2018, the last one of the 72 Swedish hospitals with a coronary care unit (CCU) joined registration and additionally, three rural CR centers report data to the registry (100%). Data entry to the registry is voluntary for all centers.

Populations and consent

From initially including 2200 patients (27%) in 2005, since 2010 the SWEDEHEART-CR registry covers approximately 8500 annual MI cases. Participating centres in SWEDEHEART-CR and number of patients registered at first follow-up per centre in 2019 is shown in Figure 2a and 2b, respectively. This represents between 75–80 % of all patients <80 years of age with an MI discharged alive from CCUs in the country and that are followed up on CR performance for the first year after MI. This corresponds to an exceptionally high CR uptake, when compared to other countries around the world (10). One major reason for the high CR uptake rate is that when registering a patient with an MI in SWEDEHEARTs ACS sub-registry (nationally referred to as RIKS-HIA), a CR follow-up is automatically generated. The SWEDEHEART-CR registry today represents a unique CR cohort of patients after MI,

both in terms of size and national representability, with data available on more than 100 000 patients.

In 2019, the average patient registered in the SWEDEHEART-CR registry was in 77% of cases male, 55% were between 60-74 years old, 40% admitted for STEMI and 87% treated with PCI during hospitalisation, 56% had hypertension and 24% diabetes, 23% were smokers (11). Compared with attenders, the 20 % not followed in the SWEDEHEART-CR registry were older, more often had prior cardiovascular disease, and had a higher prevalence of cardiovascular risk factors. In Table 1 differences between attenders and non-attenders in the SWEDEHEART-CR registry from 2019 is presented (11), which is consistent with data from previous years. According to Swedish law, all patients must be informed about their participation in the registry and the right to get their data erased from the registry on request.

Start points

The SWEDEHEART-CR registry includes patients with a first time or recurrent Type 1 MI (ICD codes I21 or I22) discharged alive between the age of 18-79 years and with a Swedish personal identification number. The age limit was increased from 74 to 79 years January 1st, 2018, in concordance with longer life-expectancy and better survival after MI. There are no exclusion criteria.

Baseline and follow-up data

Variables in the SWEDEHEART-CR registry are carefully reviewed by the registry working group to ensure that they remain up-to-date and reflect contemporary evidence-based practice. More than 80 variables describing CR-performance are registered at four time-fixed follow-up visits. These include two visits to a nurse or physician, at two-months (time frame 6-10 weeks) and one-year (time frame 11-13 months) after MI, and two visits to a physiotherapist

at start and end of an exercise-based CR programme (12). An overview of the SWEDEHEART-CR registry follow-up visits can be found in Figure 3.

Variables registered at the nurse/physician visits include information on the patients´ weight and waist circumference, systolic and diastolic blood pressure, blood tests (fasting plasma glucose, HbA1c and lipid status), comorbidities, use of medication, psychosocial and lifestyle variables (smoking, diet and physical activity), incidence of cardiac symptoms, health-related quality of life, participation in selected components of the CR programmes, such as exercise-based CR and patient education programme, and readmissions after initial discharge.

Variables registered at the physiotherapist visits (included in the registry since 2016) include submaximal exercise capacity on a bicycle ergometer, two muscular endurance tests and five patient-reported outcome measures on physical activity, exercise, and physical capacity. A complete variable list is found as Supplementary Data.

The SWEDEHEART Quality Index contains 11 indicators that reflect the quality of the whole chain of patient care five of which are collected from SWEDEHEART-CR: 1) the proportion of smokers at baseline abstinent from smoking at one-year post MI, the proportion of patients reaching a 2) systolic blood pressure < 140 mmHg and 3) LDL-C < 1.8 mmol/L (< 1.4 mmol/L from January 1st, 2021) at one-year post MI, 4) the proportion of patients participating in an exercise-based CR programme, and 5) proportion of patients attending a post CR programme evaluation (Table 2). A standardized methodology for the development of quality indicators in CVD have recently been suggested by the ESC to ensure that indicators are clinically relevant, scientifically justified, and usable (19). However, the Quality Index in SWEDEHEART was developed as a national consensus before this international methodology was established.

Data capture and storage

The SWEDEHEART-CR interactive web-based IT-platform is an integral part of the SWEDEHEART IT infrastructure developed and maintained by Uppsala Clinical Research Centre (UCR; http://www.ucr.uu.se). All data in SWEDEHEART-CR is registered by health care professionals online and transferred in an encrypted format to a central server.

Data quality

To ensure data quality, the data platform has error checking for range and consistency. Definitions are displayed on the screen when data are entered. To reach a high degree of completeness most of the variables in the SWEDEHEART-CR registry are mandatory. The SWEDEHEART-CR working group provides manuals while education and support are given by the monitor organization. To certify the correctness of the data entered, monitoring of SWEDEHEART-CR data is performed in two-year cycles, including 30 randomly selected patients at each participating center. The monitoring has consistently confirmed >95% agreement with data from medical records.

Linkages to other data

As every Swedish citizen has a unique personal identification number, merging data from SWEDEHEART-CR with other national registries is possible. In the merging process data is pseudonymized and patient identity is removed from the database. Transferring pseudonymized data outside Sweden requires special approvals and permissions and have until now been uncommon.

Access to data

Hospitals have direct access to their own data, to be used for local auditing and quality improvement. An approval from the Swedish Ethical Review Authority is needed for all research using SWEDEHEART-CR data. Data applications are sent to and administered by UCR. A research advisory board, independent from the SWEDEHEART steering committee, performs a first review of all research applications and ethical approvals.

Conclusions

The SWEDEHEART-CR registry represents an internationally unique continuously growing real-world cohort of patients with a recent MI, with nationwide coverage and high patient representation. As such, the SWEDEHEART-CR provides an unequivocal base to improve secondary preventive care in Sweden and to produce high impact research. The long-term goal is to contribute to reduced mortality and morbidity in patients having suffered an MI, and to improve the cost-effectiveness of patient care.

Supplementary Data

SWEDEHEART-CR variable list.

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None.

Conflict of interest

Dr. Hagström reports grants and personal fees from Amgen, Bayer and Sanofi outside the submitted work; Dr. Jernberg reports institutional grants from Novartis and fees for consulting and lecturing from Astra Zeneca, Bayer, Novartis and Sanofi outside the submitted work; Dr. Norhammar reports personal fees from Honorarium Astra Zeneca, Lilly, Boehringer Ingelheim, Novo Nordisk, MSD, outside the submitted work.

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Figure legends

Figure 1. SWEDEHEART organizational chart. RIKSHIA, Swedish Register of Information and Knowledge about Swedish Heart Intensive Care; SCAAR, Swedish Coronary Angiography and Angioplasty Registry; SEPHIA, Secondary Prevention after Heart Intensive Care Admission; SWENTRY, Swedish Transcatheter Cardiac Intervention Registry; AURICULA, Swedish Registry of atrial fibrillation and anticoagulation.

Figure 2a. Participating centres in SWEDEHEART-CR in 2019. Reprinted with permission from SWEDEHEART.

Figure 2b. Patient coverage and demographics. Number of patients registered at 1st follow-up, per centre, in 2019. Apart from the total number of patients per CR centre, the figure shows the proportion of patients in the age group 75-79 years registered at each center (light blue). Reprinted with permission from SWEDEHEART.

Figure 3. Overview of SWEDEHEART-CR registry (SEPHIA) follow-up visits. AMI, acute myocardial infarction; RIKSHIA, Swedish Register of Information and Knowledge about Swedish Heart Intensive care Admission; PT, physiotherapist.

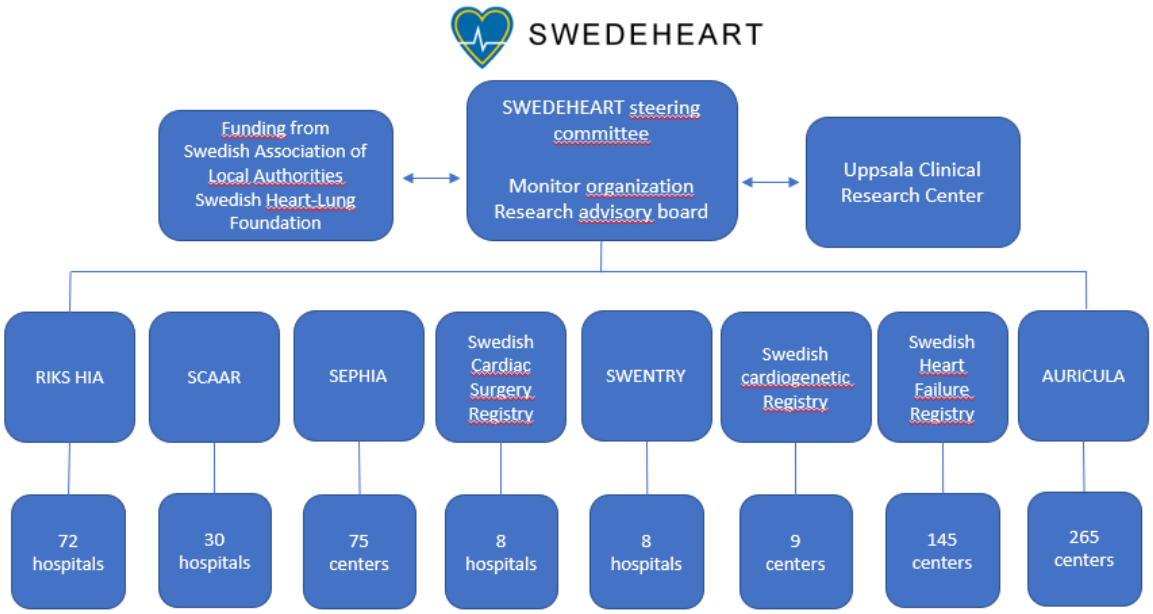

SWEDEHEART
Funding from Swedish Association of Local Authorities Swedish Heart-Lung Foundation
SWEDEHEART steering committee
Monitor organization
Research advisory board
Uppsala Clinical Research Center
RIKS HIA
SCAAR
SEPHIA
Swedish Cardiac Surgery Registry
SWENTRY
Swedish cardiogenetic Registry
Swedish Heart Failure Registry
AURICULA
72 hospitals
30 hospitals
75 centers
8 hospitals
8 hospitals
9 centers
145 centers
265 centers

Figure 1.

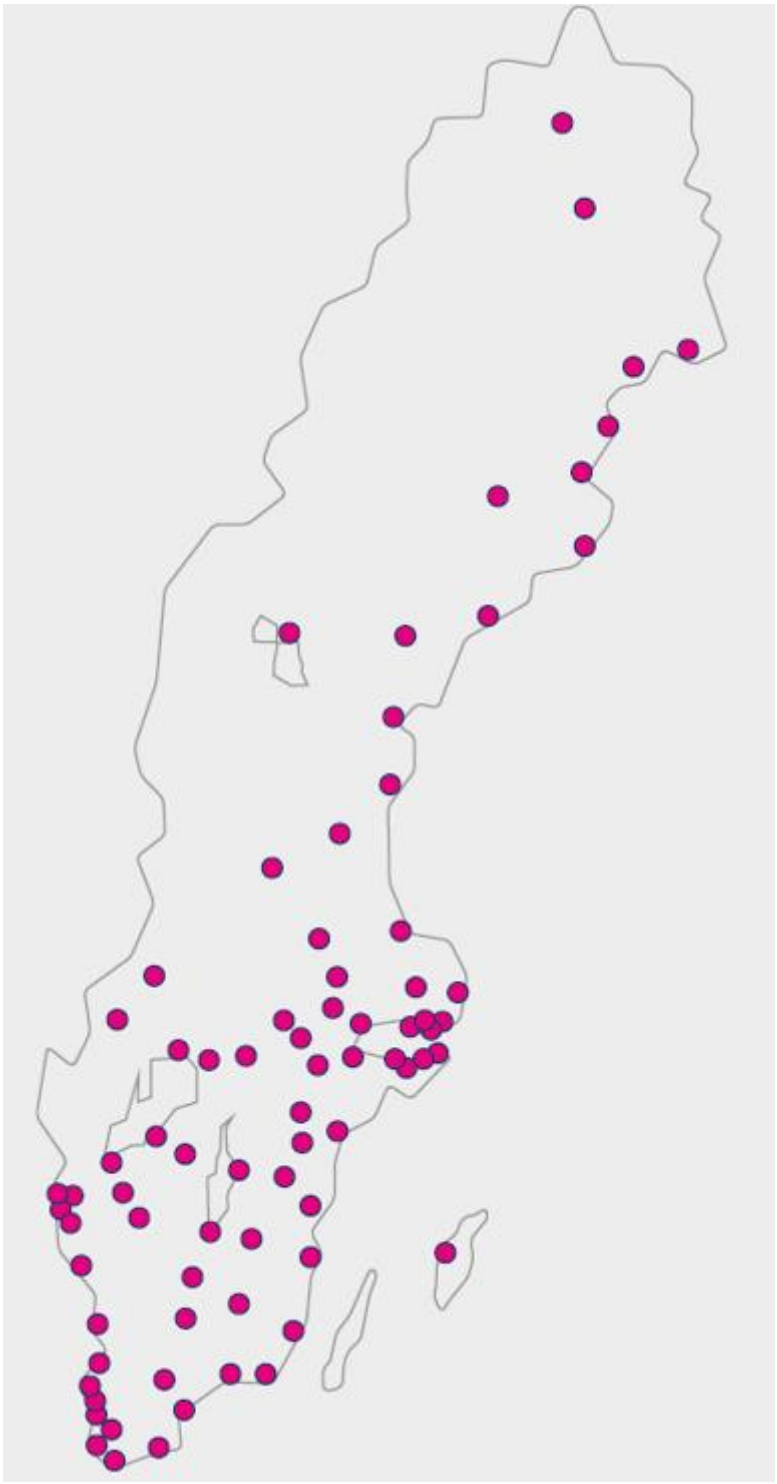
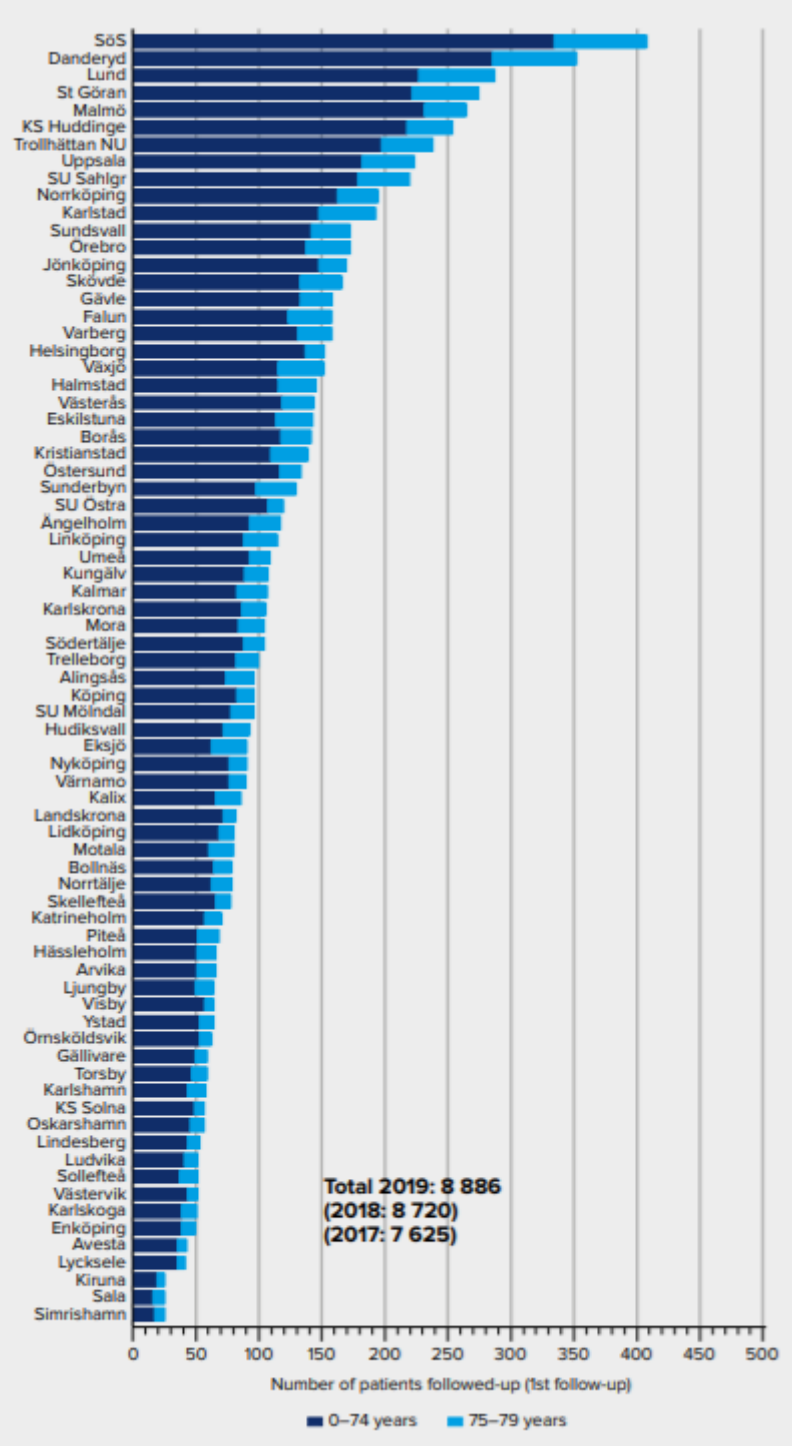


Figure 2a.


SöS
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Trollhättan NU
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Sundsvall
Örebro
Jönköping
Skövde
Gävle
Falun
Varberg
Helsingborg
Växjö
Halmstad
Västerås
Eskilstuna
Borås
Kristianstad
Östersund
Sunderbyn
SU Östra
Ängelholm
Linköping
Umeå
Kungälv
Kalmar
Karlskrona
Mora
Södertälje
Trelleborg
Alingsås
Köping
SU Mölndal
Hudiksvall
Eksjö
Nyköping
Värnamo
Kalix
Landskrona
Lidköping
Motala
Bollnäs
Norrtälje
Skellefteå
Katrineholm
Piteå
Hässleholm
Arvika
Ljungby
Visby
Ystad
Örnsköldsvik
Gällivare
Torsby
Karlshamn
KS Solna
Oskarshamn
Lindesberg
Ludvika
Sollefteå
Västervik
Karlskoga
Enköping
Avesta
Lycksele
Kiruna
Sala
Simrishamn
Total 2019: 8 886
(2018: 8 720)
(2017: 7 625)
0
50
100
150
200
250
300
350
400
450
500
Number of patients followed-up (1st follow-up)
0–74 years
75–79 years

Figure 2b.

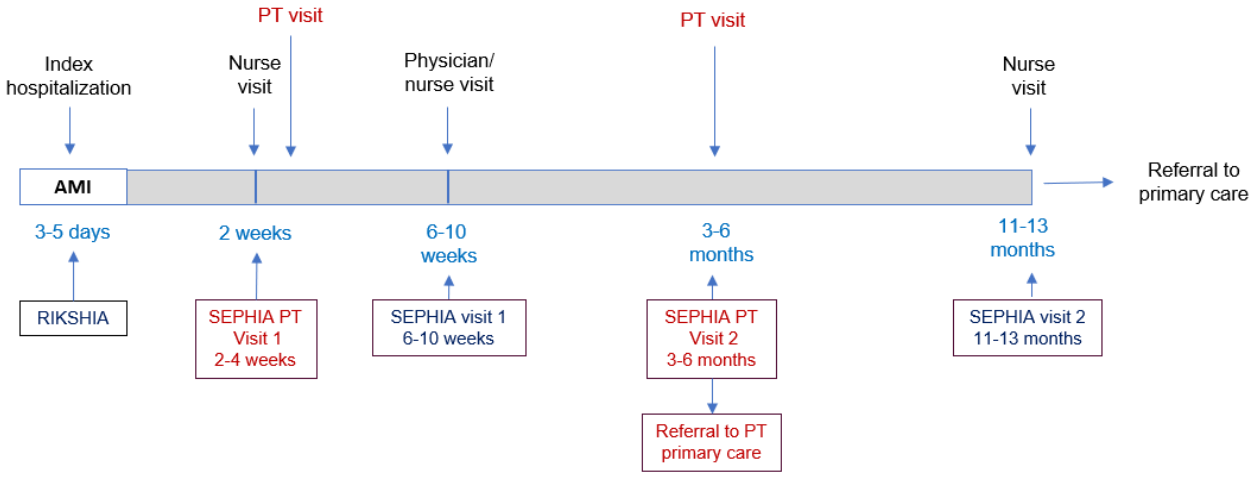
PT visit
PT visit
Index hospitalization
Nurse visit
Physician/ nurse visit
Nurse visit
AMI
Referral to primary care
3-5 days
2 weeks
6-10 weeks
3-6 months
11-13 months
RIKSHIA
SEPHIA PT Visit 1 2-4 weeks
SEPHIA visit 1 6-10 weeks
SEPHIA PT Visit 2 3-6 months
SEPHIA visit 2 11-13 months
Referral to PT primary care

Figure 3

Table 1. Baseline characteristics for patients followed in the SWEDEHEART-CR registry versus those not followed in 2019.

		Followed in SWEDEHEART-CR		Not followed in SWEDEHEART-CR	
		Number	**(%)**	**Number**	**(%)**
Patients - number and proportion		8862	100	2261	100
Gender	Male	6598	74	1633	72
	Female	2264	26	628	28
Age groups	< 60 years	2335	26	544	24
	60-69 years	2926	33	742	33
	70-74 years	1939	22	477	21
	75-79 years	1662	19	498	22
Hypertension	Yes	4992	56	1497	66
Diabetes mellitus	Yes	2136	24	772	34
Previous AMI	Yes	1650	19	823	36
History of impaired LV function	Yes	457	5	287	13
Previous stroke	Yes	385	4	205	9
Previous PCI	Yes	1500	17	706	31
Previous cardiac surgery	CABG	465	5	238	11
	Other cardiac surgery	44	0	7	0
Smoking	Ex-smoker >1 month	3314	37	837	37
	Smoker	2051	23	559	25
Coronary angiography	Yes	8749	99	2018	89
PCI	Yes, during hospital stay	7676	87	1576	70
	Planned after discharge	12	0	8	0
CABG	Yes, during hospital stay	539	6	206	9
	Planned after discharge	170	2	82	4
	Yes, emergency CABG	5	0	5	0
LV function (%)	Normal (≥50 %)	5447	66	1149	58
	Mildly reduced (41-50 %)	1763	21	449	23
	Moderately reduced (31-40 %)	772	9	240	12
	Severely reduced (< 30 %)	259	3	120	6
	Unknown	33	0	13	1
Type of AMI	NSTEMI	5361	60	1598	71
	STEMI	3501	40	663	29

AMI, acute myocardial infarction; LV, left ventricular; PCI, percutaneous coronary intervention; CABG, coronary artery bypass grafting; STEMI, ST-elevation myocardial infarction, NSTEMI, non-ST-elevation myocardial infarction

Table 2. The SWEDEHEART Quality Index

Quality Indicator	**0.5 points (%)**	**1 point (%)**
Reperfusion in STEMI	80	85
Reperfusion in STEMI within recommended time	75	90
Coronary angiography within 72 hours in target group in NSTEMI	75	80
P2Y12 blockers in NSTEMI	85	90
ACE/ARB in target group for MI	85	90
Proportion with MI as principal diagnosis (<80 years) included in RIKS-HIA	90	95
Proportion of MI < 80 years attending a post CR programme evaluation	75	90
Proportion of smokers who have stopped after 11-13 months	60	70
Proportion who has taken part in an exercise-based cardiac rehabilitation programme after 11-13 months	50	60
Proportion with LDL cholesterol < 1.8 mmol/L (< 1.4 mmol/L from January 1st, 2021) after 11-13 months	40	60
Proportion with systolic blood pressure < 140 mmHg after 11-13 months	70	75

STEMI, ST-elevation myocardial infarction, NSTEMI, non-ST-elevation myocardial infarction; ACE, angiotensin converting enzyme; ARB, angiotensin receptor blockers; RIKSHIA, Swedish Register of Information and Knowledge about Swedish Heart Intensive care Admission; CR, cardiac rehabilitation; LDL, low-density lipoprotein