EuroHeart Data standards

European Unified Registries On Heart Care Evaluation and Randomized Trials

www.escardio.org/euroheart









EuroHeart – The Project

The mission of EuroHeart is to develop and maintain an international collaboration that provides general availability to systems with continuous online registration of high quality and harmonised individual patient data at entry and over time, with real-time information supporting continuous improvement of care and outcomes in patients with common cardiovascular diseases.

EuroHeart will also include an **international infrastructure** for cost-effective safety surveillance of new drugs and devices and registry based randomised clinical trials in a general patient population across multiple geographies.





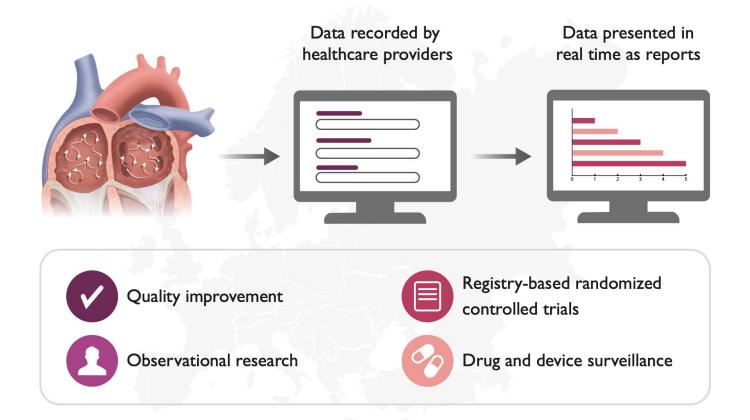
EuroHeart – The Project

- Is based on development of and **collaboration** between national programmes that use **common data sets and quality criteria**.
- Supports continuous **development of quality of care** based on **individual and harmonised patient data**.
- Integrates tools for drug and device surveillance.
- Integrates tools for registry-based randomised clinical trials (RRCT).
- Provides an optional common IT-infrastructure.





EuroHeart – The Concept



Countries joining EuroHeart through adopting the EH datasets



Mandatory variables



Data crosswalk – High level

A high level data crosswalk to identify the variables that are similar/same, different and new.

Data crosswalk – Detailed

Detailed review of variables classified as different and new and to take decision on harmonisation and prioritisation.

Step-wise harmonisation

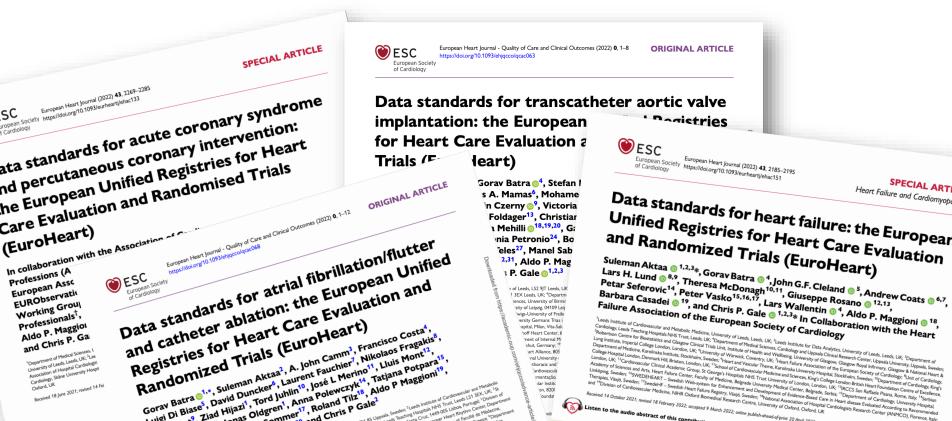
In accordance with the decisions and pace set by the national registries.

Data set review
Rough review comparing the
two datasets, at a
very high level, in
order to get the
sense of degree
of harmonisation

needed.



EuroHeart – Data standards



SPECIAL ARTIC Heart Failure and Cardiomyopath Data standards for heart failure: the European

Suleman Aktaa (5) 1,2,3*, Gorav Batra (5) 4, John G.F. Cleland (6) 5, Andrew Coats (6) 6,7, Suleman Aktaa (1) ******, Gorav Batra (1) **, John G.F. Cleland (1) **, Andrew Coats (1) **.

Lars H. Lund (1) **, Theresa McDonagh (1) **, Giuseppe Rosano (1) **, Andrew Coats (1) **, Peter Vasko (1) **, Lars Wallentin (1) **, Aldo P. Maggioni (1) **, Lars Wallentin (1) **, Aldo P. Maggioni (1) **, Lars Wallentin (1) **, Aldo P. Maggioni (1) * Barbara Casadei (6) 19, and Chris P. Gale (6) 1,2,3* In Collaboration with the Heart Leeds Institute of Cardiovascular and Metabolic Medicine, University of Leeds, Leeds, UK: Teeds Institute for Data Analytics, University of Leeds, Leeds, UK: "Department of Conductions of Standard University of Leeds, University of Leeds, Leeds, UK: "Department of Medicine Conductions and Evension Clinical Banaries, Control Evension Elevations Con

Leeds Institute of Cardiovascular and Metabolic Medicine, University of Leeds, Leeds, UK. *Leeds Institute for Data Analytics, University of Leeds, Leeds, UK. *Department of Medical Sciences, Cardiology, Leeds Practice Proposition of Proceedings of Leeds (Leeds, UK. *Department of Medical Sciences, Cardiology and Uppsala Clinical Research Center, Uppsala University, Uppsala University, Uppsala University, Uppsala University, Uppsala Sciences, Cardiology and Uppsala Clinical Research Center, Uppsala University, Uppsala University, Uppsala Sciences, Cardiology and Uppsala University, Uppsala University, Uppsala University, Uppsala Sciences, Cardiology, University of Leeds, Leeds, UK. *Department of Uppsala University, Uppsala University, Uppsala University, Uppsala Sciences, Cardiology, University of Leeds, Leeds, UK. *Department of Uppsala University, Upp Cardology Leds Teaching Hospitals NHS Trust, Leeds, UK: "Department of Medical Sciences, Cardology and Uppsala Clinical Research Center, Uppsala University, Uppsala, Sweders, "Robertson Center for Biostatistics and Glasgow Clinical Trials Unit, Institute of Health and Wellbeing, University of Glasgow, Glasgow Royal Informacy, Glasgow, Alaborat Hospitals, Sweders, "Annual Product Landon Lando Robertson Centre for Biostatistics and Glasgow Cincal Trials Unit, Institute of Health and Welbeing, University of Glasgow, Glasgow Royal Informary, Glasgow & National Heart & Lang Institute, Imperial College London, London, LK, "University of Willworks, Corentry, UK," Heart Failure Association of the European Society of Cardology, "University of Cardology," University of Cardolo Lung Institute, Imperial College London, London, LK, "Leiversity of Warwick, Coventry, UK," Heart Failure Association of the European Society of Cardiology, "Unit of Cardiology," "Unit of Cardiology, "Unit of Cardiology, "Unit of Cardiology," "Unit Department of Medicine, Karolinska Institute, Stockholm, Sweder, "Heart and Vascular Theme, Karolinska Luhversky Hospital, Stockholm, Sweder, "Department of Cardology, Kings College Hospital London, Demunik Hill Britton, London, U.K. "School of Cardonoscular Medicine and Sciences, King's College London British Heart Foundation, Central Landon, U.K. "School of Cardonoscular Medicine and Sciences, King's College London British Heart Foundation, Central Landon, U.K. "School of Cardonoscular Medicine and Sciences, King's College London British Heart Foundation, Central Landon, U.K. "School of Cardonoscular Medicine and Sciences, King's College London British Heart Foundation, Central Landon, U.K. "School of Cardonoscular Medicine and Sciences, King's College London British Heart Foundation, Central Landon, U.K. "School of Cardonoscular Medicine and Sciences, King's College London British Heart Foundation, Central Landon, U.K. "School of Cardonoscular Medicine and Sciences, King's College London British Heart Foundation, Central Landon, U.K. "School of Cardonoscular Medicine and Sciences, King's College London British Heart Foundation, Central Landon, U.K. "School of Cardonoscular Medicine and Sciences, King's College London British Heart Foundation, Central Landon, U.K. "School of Cardonoscular Medicine and Sciences, King's College London British Heart Foundation, Central Landon, U.K. "School of Cardonoscular Medicine and Sciences, King's College London British Heart Foundation, Central Landon, U.K. "School of Cardonoscular Medicine and Sciences, King's College London British Heart Foundation, Central Landon, U.K. "School of Cardonoscular Medicine and Sciences, King's College London, U.K. "School of Cardonoscular Medicine and Sciences, King's College London, U.K. "School of Cardonoscular Medicine and Sciences, King's College London, U.K. "School of Cardonoscular Medicine and Sciences, King's College London, U.K. "School of Cardonoscular Medicine and Sciences, King's College London, U.K. "School of Cardonoscular Med College Hospital Jordon, Denmark Hill Briddin, London, UK. "School of Cardiovascular Medicine and Somces, King's College London British Heart Foundation Centre of Excellence London, UK, "Loardiovascular Clinical Academic Group, St. George's Hospitals NAS Trust University of London, London, UK, "Ilp.CCS San Raffelor Possus, Roman Australian Control of Management of Management Association and Management and Management of Management and Management of Management of Management and Management of Management and Management of Management London, UK, "Cardiovascular Citical Academic Group, St. George's Hospitals NHS Triat University of London, London, UK, "IRCCS San Raiffaele Plana, Rome, Italy, "Serblan Academy of Sciences and Arts, Heart Failure Center, Fiscally of Medicine, Belgrade, University Medical Center, Belgrade, Seebs, "Department of Cardiology, University Hospital, Control, Medicine, Business Gaussian, "ICXLETICAL BEY"—Gaussian, Machinessan, Machinessan Academy of Sciences and Arts, Heart Failure Center, Faculty of Medicine, Belgrade University Medical Center, Belgrade, Serbig: "Popurtment of Cardiology, University Hospital Linkspring, Swedger, "SNYEDEHEART" - Swedish Web-systems for Enhancement and Development of Suddence-Based Care in Heart disease Enablated According to Recommendate Union, Country, Vision Country, Vision Country, Vision Country, Physical Association, of Educated Care in Heart disease Enhanced Cardiology, University Hospital Cardiology Linkoping, Sweder, "SWEDEREART – Swedish Web-system for Enhancement and Development of Evidence-Based Cure in Heart disease Evakated According to Recommended Throughes, Visigo, Sweder, "Swedish Heart Failure Registry, Visigo, Sweder," "National Association of Hospital Cardiologists Research Center (ANHCO), Rorence, Bally-Received 14 October 2021; revised 18 February 2022; accepted 9 March 2022; anilyn nublish-abunduslanius 20 Aurus 20

Listen to the audio abstract of this contril



EuroHeart – Data standards

EuroHeart-EuroHeart-EuroHeart-EuroHeart-EuroHeart-Heart failure Atrial fibrillation ACS PCI **TAVI** EuroHeart – Level 1 (mandatory) variables EuroHeart – Level 2 (additional) variables EuroHeart – Level 3 (country-specific) variables EuroHeart – Outcome module EuroHeart – Drug and device module EuroHeart – R-RCT module



EuroHeart – Data standards

Euı	roHeart- ACS	EuroHeart- PCI	EuroHeart- Heart failure	EuroHeart- Atrial fibrillation	EuroHeart- TAVI
Level 1	68	84	84	70	93
Level 2	90	55	79	92	113



EuroHeart – Data standards for CV outcomes

Aim

Will be used in future randomised trials and observational Studies

Outcome domains

- General CV outcomes
- Domain specific outcomes
 - Acute coronary syndrome and PCI
 - Heart failure
 - Atrial fibrillation
 - TAVI

Step 1

 Identification of clinical cardiovascular domains

Step 2

- Defining specifications
- Systematic literature review

Step 3

 Selection of variables, permissible values and definitions

Step 4

- Wider validation
- Formal endorsement
- Publication

Step 5

• Implementation into the EuroHeart IT platform

Methodology for the development of international clinical data standards for common cardiovascular conditions: Lundied Registries for Heart Care Evaluation Unified Registries for Heart Care Evaluation and Randomised Trials (EuroHeart).



EuroHeart – Data standards for PROMs

Aim

To develop a unified Data Standards for CV PROMs and to implement it into the EuroHeart IT platform

Outcome domains

- General CV PROMs
- Domain specific PROMs
 - Acute coronary syndrome and PCI
 - Heart failure
 - Atrial fibrillation
 - TAVI

Step 1

 Identification of clinical cardiovascular domains

Step 2

- Defining specifications
- Systematic literature review

Step 3

 Selection of variables, permissible values and definitions

Step 4

- Wider validation
- Formal endorsement
- Publication

Step 5

 Implementation into the EuroHeart IT platform



EuroHeart Network

EuroHeart

Estonia

7. Ireland

England and 8. Italy

Wales

9. Lithuania

Denmark

10. Portugal

France

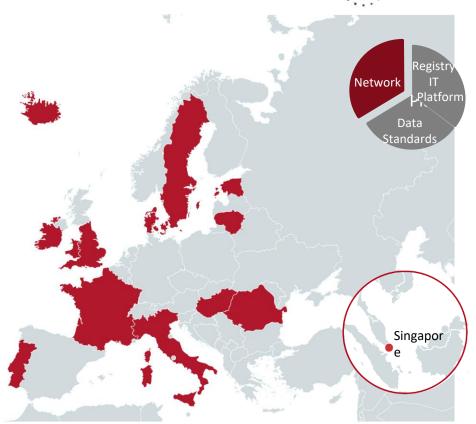
11. Romania

Hungary

12. Singapore

Iceland

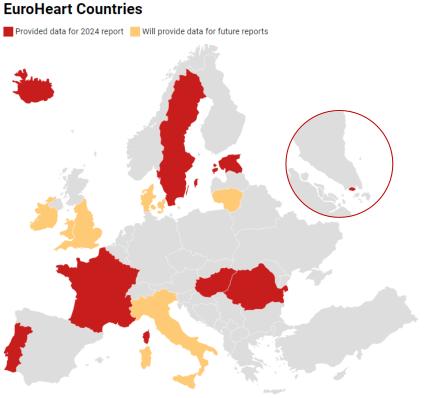
13. Sweden



2024 Report: 63,960 ACS and 46,971 PCI submissions

EuroHeart

- Eight countries: Estonia, France,
 Hungary, Iceland, Romania, Portugal,
 Singapore, Sweden.
- Final diagnosis of STEMI or NSTEMI
- Analysis stratified by diabetes status





EuroHeart – Registry IT-platform



EuroHeart as a core ESC activity from 2025



Core activities

Support and develop the existing network of countries/registries

- Improve data quality and coverage
- Expand to additional registry domains

Regularly report on quality of care aligned with ESC guidelines

Development activities

Apply federated data analysis

Support automated data capture

Generate new evidence

Consider the
EuroHeart IT for
possible ESC
accreditation schemes



EuroHeart – More information

www.escardio.org/euroheart

euroheart@escardio.org