EuroHeart
European Unified Registries for Heart Care Evaluation and Randomised Trials

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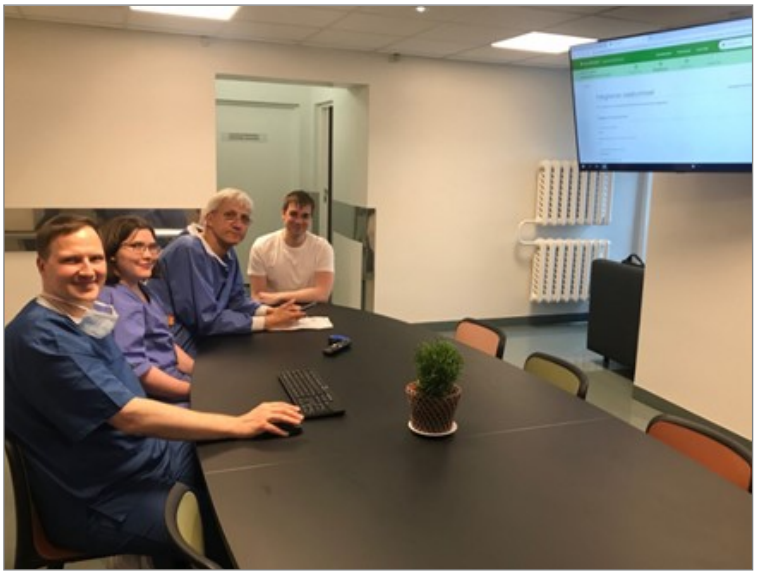
Milestone celebrations

Estonia: First patient in the ACS-PCI registry

Hungary: Harmonisation of the ACS EuroHeart Data Standard completed!

On 3 May, the first patient was registered in the ACS-PCI registry in Estonia, which is the first registry built on the EuroHeart common IT-registry platform. According to Richard Jalakas, the IT Project Manager of the Estonia team, this was the most exciting moment during the EuroHeart implementation period so far. We interviewed Dr Alar Irs, the National EuroHeart Project Lead from the Estonian Society of Cardiology and Richard Jalakas – read the inspiring story on pages 2-4.



"We hope to achieve a common registry platform that is integrated with electronic health records and national health databases, enabling single data entry, automated data collection where possible, linkage for outcomes and outputs on quality of care that will be available to health care providers, payers and patients. The concept that ESC has developed is simple, doable and will provide direct patient benefit with additional bonuses." - Dr Alar Irs.

"The timing of the EuroHeart project is truly perfect! In my view, the EuroHeart project offers a platform – and not only a technical platform — that will enable us to support daily quality and R&D activities around the provision of cardiac care. Do not hesitate to join the EuroHeart project. There is a lot of support from the community – the ESC, Uppsala Clinical Research Centre — and in the future, surely all the pilot countries will be ready to help and encourage when needed." - Richard Jalakas.

EuroHeart Data Standards

The **Data Standards for ACS-PCI** have been submitted for publication, and implementation is starting in several countries.

The first version of the **Data Standards for Heart Failure** has been developed and comprises 84 level one (mandatory) variables across seven domains of heart failure care extending from baseline characteristics, clinical status and medications. Currently, the EuroHeart Data Science Group is approaching ESC Working Groups and the National Cardiac Societies for endorsement.

The **Data Standards for Atrial Fibrillation** and **Transcatheter Aortic Valve Implantation** are currently in preparation. We are in the process of meeting international experts, patient representatives and approaching relevant ESC Associations.

The **Atrial Fibrillation Data Standards** reference group comprises over 60 members from around 30 countries. A systematic review of the literature has been completed, and the first Delphi round has recently been finalised. Currently, a series of meetings are taking place to reach a final agreement on the data fields.

EuroHeart pilot phase - extended until June 30, 2022

Based on delays caused by the COVID-19 pandemic, the EuroHeart pilot phase has been extended by six months until 30 June, 2022. During the remaining year, we will continue the interaction with interested countries, finalise the data standards for the four disease domains, finalise the development of the EuroHeart registry IT-platform for these disease areas and continue registering patients.

Interview with Estonia

Alar Irs, *Estonian Society of Cardiology and National EuroHeart Project Lead*

Q: Why did Estonia decide to join EuroHeart?

Alar Irs: Cardiovascular disease is still the top contributor to morbidity and mortality in the country. Its management consumes a fair share of the health care budget, and it is imperative that we provide quality in care and that spending improves outcomes. Data on quality were in short supply in all cardiovascular disease areas except for myocardial infarction, and even there, the national registry has quite a lag time as the results are published annually. It has also been somewhat painful to notice Estonia painted grey in presentations on epidemiology or quality of care to denote missing data. Equally importantly for a tiny country, we hope it will improve our options to be part of international academic and applied research networks.

Q: Did Estonia have cardiac quality registries before joining EuroHeart, or did you develop the registry from scratch?

Alar Irs: Estonia has a long record of registry studies in myocardial infarction, starting in the early 1990s. The longitudinal national myocardial infarction registry was established in 2012 and has provided excellent data for quality improvement and for research. Participation is mandatory for all health service providers, and this enables almost complete coverage. There are however very limited datasets on other important cardiovascular diseases and their management.

Q: Why did you place the ACS-PCI registry at Tartu University Hospital, and did you consider other options such as the Ministry of Health?

Alar Irs: The current Estonian national myocardial infarction registry is hosted by Tartu University Hospital. Other national registries are kept at the National Institute for Health Development, and discussions are ongoing about the strategic future of health care datasets.

To meet our deadline, we had to use an existing data infrastructure, ready to deal with the regulatory requirements. None of the central governmental institutions was able to react in the timeframe needed for the ESC pilot. In the long run, 4-5 years, it seems plausible to relocate the registry platform to a central governmental host once this has been set up by the National Health and Welfare Information Systems Centre. But this is not seen as a must.

Q: Could you please describe the national team implementing the EuroHeart project?

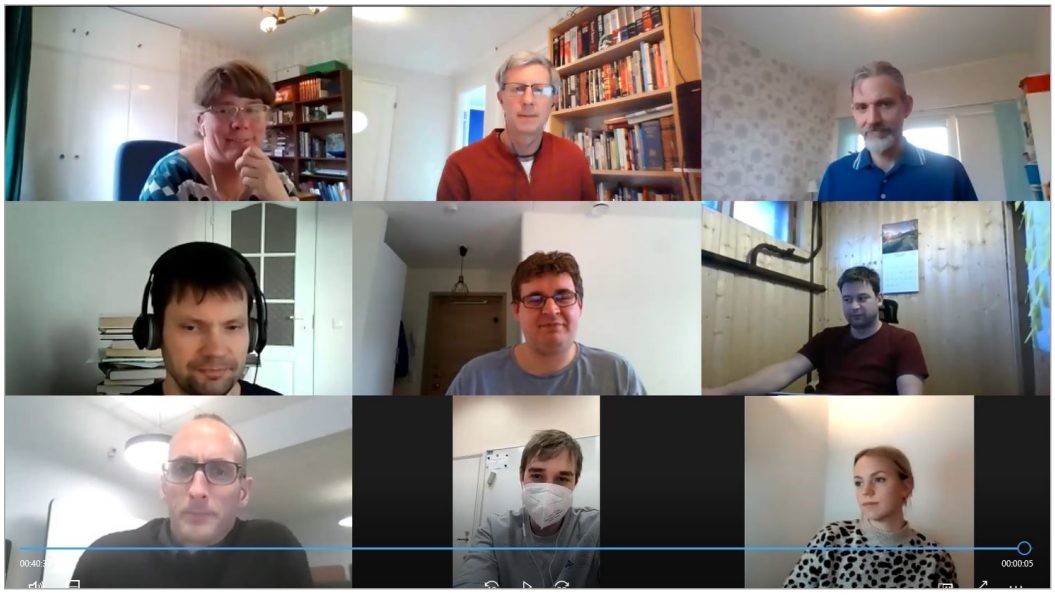
Alar Irs: One of the board members of the Estonian Society of Cardiology has been appointed as responsible for the project.

There are two layers of activity – the central implementation of the IT platform at Tartu University Hospital (TUH) plus the dialogue with national stakeholders and the involvement of the centres (five different hospitals at the pilot stage).

For the central implementation, we have an IT project manager, clinical lead, host institution IT colleagues (led by the Chief Information Officer of the hospital) and external IT partners (e.g. for analysis and technical development). Legal and procurement support from the host institution has also been necessary. As we launch the modules and data collection in participating centres, we plan to involve the TUH Clinical Research Centre's monitoring staff.

We are recruiting a clinical lead for each institution, who, together with the central team, form the main working group for the project. Depending on the financing available, we intend to integrate the registry platform with the eHRs (we have three different in the participating hospitals), for each an additional IT specialist is added to the team.

Richard Jalakas,
IT Project Manager



A zoom-workshop session on the implementation of the EuroHeart IT-platform between Estonia Registry Centre and the EuroHeart Registry Technology Team

Q: Could you please describe the national team implementing the EuroHeart project?

Richard Jalakas: In our case, as we have a small team, we quite often work like a start-up. We develop the vision of what must be done from the clinical side and who has to be involved in the project phase we currently are in. I, as an IT project manager, try to make sure we deliver technical developments on time, offer technical support to clinical staff and help with other project management activities when needed. TUH IT is responsible for system administration related activities. And we have an IT development partner Quretec with experience in health registries software who executes the needed technical developments, e.g. the integration with population registry etc.

Q: Could you please give some examples of national adaptations made to implement the EuroHeart IT-platform?

Richard Jalakas: We have implemented our own electronic authentication methods so the health care professionals can easily and securely log into the EuroHeart platform by using an Estonian ID-card, smart -ID or mobile-ID. We are working on integrating the EuroHeart platform into our population registry and electronic health records. The integration with relevant information systems and databases is really important for us so we can re-use already existing data and enable single data entry.

Q: Could you please share the most exciting moment during the EuroHeart implementation period?

Richard Jalakas: For sure, it has to be the moment when the first ACS patient was entered into the Estonian EuroHeart registry platform on May 3, 2021.

Q: What efforts have you made to ensure the cardiologists are on board and supportive?

Richard Jalakas: I think it is most important to have a dedicated clinical champion who knows how to engage people.

Alar Irs: Let us not declare a victory yet; we are at the beginning of a journey. The board of the Estonian Cardiac Society has been very supportive of the idea, as well as the clinical leaders of the participating hospitals. The devil is however in the detail, and the data collection and entry is an extra burden to busy clinicians – at least until we achieve integration with eHRs.

We had an introductory webinar with Professor Lars Wallentin to explain the wider context and the value of the project to the physicians involved in ACS care. We have also asked the working group of young cardiologists of the Estonian Society of Cardiology for their help – youth always appreciate a good challenge. Plus, our colleagues are acutely aware of the responsibility we have as the first pilot country.

In practical terms, we are introducing the data collection step-wise in the first centre and expect to collect feedback for improving the system over this summer. As we are quite IT-friendly as a country and as a health system, the expectations for any new system are high, and it must be as user-friendly as possible.

Q: How do you describe your experiences working with EuroHeart Technical Team?

Richard Jalakas: The technical team have been very supportive and always available for our questions and suggestions. We also appreciate that the EuroHeart technical team has accommodated some of the delays in our own work plan regarding the national technical developments. The technical team has vast experience and the idea to establish a separate customer support portal and a knowledge centre for technical information and specification is excellent. Surely all the next pilot countries can proceed faster by leveraging these resources (and all our well documented first stumbles).

Q: What have been the most striking challenge with implementing the EuroHeart IT-platform so far?

Alar Irs: It has been an enjoyable journey, and we have had wonderful counterparts at the ESC and Uppsala Clinical Research Centre. The main challenging feature of the project is that it is so dynamic. It is not common for hospital IT staff to face a tool-box type of platform which is still under development at the time we go live with the first modules. The same applies to clinical colleagues who would like to have the speedometer showing the level of quality indicators from day 1 while the introduction of the platform is gradual. And the expectation management, as said, the expectations to any new IT tool in this country are very high.

Richard Jalakas: In my opinion, communication with relevant stakeholders is where the difficulty lies. We have multiple hospitals, an IT-development partner company, the National Health Insurance Fund (the payer and national quality of care indicator developer) and several governmental institutions on board in this project – all having various interests and ideas. Therefore, it has sometimes been difficult to explain why we did not involve a particular party earlier, or why some functionalities are technically in development, or why additional funding is needed.

Q: Please describe some challenges harmonising the EuroHeart standard variables and quality indicators with your established national registry?

Alar Irs: It would surely have been more comfortable to start with a disease area where no previous national data collection was in place. Some of the EuroHeart ACS variables are defined differently compared to our current national registry, but it helps that the EuroHeart definitions come from an ESC-wide process and are linked to the current recommended quality indicators. We need to find ways to reconcile the longitudinal data, though.

Q: There are many who look forward to running R-RCT in the EuroHeart network. If you were responsible for an R-RCT, what research question would you like to answer?

Alar Irs: Oh, there are so many questions that no commercial sponsor would pick up. As an interventional cardiologist, questions about the coronary and valve patients at the borderline between interventional and surgical treatment immediately jump to my mind. But it would be good to know the actual value of all types of currently promoted interventions targeted at self-monitoring, lifestyle and treatment adherence.

Q: Where do you see your national registries and national EuroHeart activities in five years?

Alar Irs: We hope to achieve a common registry platform that is integrated with electronic health records and with national health databases, enabling single data entry, automated data collection where possible, linkage for outcomes and outputs on quality of care available to the health care providers, payers and patients. We also aim to further promote the idea of quality measurement as a prerequisite for quality improvement among health professionals. And we hope a boost to research.

Richard Jalakas: It seems to me that the timing of the EuroHeart project is truly perfect! Look at what is happening in health care now – sincere exploration of the possibilities brought by the usage of the real-world data and data analytics, moving towards value-based care, optimising care pathways etc. In my view, the EuroHeart project offers a platform that will enable us to support daily quality and R&D activities around the provision of cardiac care.

Q: What is your advice to other countries that want to implement EuroHeart in their countries?

Alar Irs: First, reflect on the beauty of the idea. The concept the ESC has developed is simple, doable and will provide direct patient benefit with additional bonuses. On a more serious note, perhaps list the reasons why you should do it in your country and get a consensus of critical stakeholders. Both will prove handy at the inevitable difficult moments during the implementation. You must also involve the next generation of healthcare professionals.

Richard Jalakas: Do not hesitate to join the EuroHeart project. There is a lot of support from the community – the ESC, Uppsala Clinical Research Centre, and in the future, surely all the pilot countries will be ready to help and encourage when needed.