



THE EACTS Quality Improvement Programme (QUIP) 2017

The latest QUIP developments

Stephanie Halksworth

QUIP Coodinator, EACTS, Windsor, UK

ver the past year, the involvement in the EACTS Quality Improvement Programme (QUIP) has accelerated rapidly, expanding to more countries and recruiting more hospitals than ever before. Since January 2016, the number of cardiothoracic procedures in the QUIP Adult Cardiac Database has doubled: the database currently holds 70,382 procedures, from 44 centres across Europe. Read more to find out about the QUIP initiatives and latest developments.

What is the EACTS QUIP?

The EACTS QUIP was established in 2012, to improve clinical outcomes for patients and to promote the integration of quality enhancing initiatives into daily clinical practice. The EACTS QUIP operates two databases with the aim of achieving this: the Adult Cardiac Database (ACD) and EUROMACS.

The QUIP Adult Cardiac Database (ACD)

Launched in 2015, the EACTS QUIP ACD is a collaborative registry of cardiac surgical data. Cardiothoracic surgical units from 44 centres across 10 European countries, are currently contributing to the QUIP ACD, through which they can take advantage of the QUIP features and benchmarking tool. In just 2 years, 66 centres have signed the QUIP Charter, and are actively contributing, or in the process of data mapping to enable them to contribute, to the QUIP ACD.

Who can benefit from the benchmarking tool?

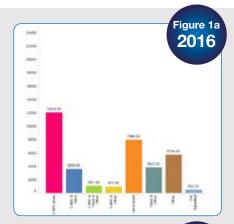
All the participating centres, with data in the registry, can benefit from the ACD benchmarking tool using individual login details provided by the University Hospitals Birmingham (UHB; UK) team. The access is given once the centre starts contributing to the database.

We have also developed a demo version of the benchmarking tool for potential participants to experience and explore the different features that will be available to them. This gives them an opportunity to preview these features and the different possibilities available before they sign up and agree to contribute data.

"The QUIP Adult Cardiac Database currently holds **70,382** procedures from **44** centres across Europe"

What are the benefits of the QUIP ACD?

The QUIP ACD has several useful tools and allows hospitals to compare anonymised data from surgical procedures on an international scale. The database's benchmarking tool enables surgeons to draw comparable data analyses with other hospitals completely anonymously. In time, as the database is developed further, contributing hospitals will receive standard, individualised reports for their centre, and using this data, will have the opportunity to carry out studies and research. Furthermore, the clinical support tool feature will enable hospitals to draw statistics for a specified criterion, helping to provide an understanding of the risks in a wider population. Figure 1 illustrates the volume of procedures, per procedure group, in the QUIP ACD in 2016 (1a) and currently in 2017 (1b); this has doubled since January 2016.





Want to try the QUIP ACD benchmarking tool?

Hina Waheed, our QUIP Statistical Intelligence Analyst at the UHB, can provide you with access to our demo version giving you the chance to try out the tool and explore its numerous features. If you would like this opportunity, please email Hina at hina.waheed@uhb.nhs.uk

Have you used the QUIP ACD benchmarking tool?

Whether you have accessed the QUIP ACD Demo tool or your centre is contributing to the real tool, we would like to hear your feedback.

Please take our QUIP Survey here: https://eacts.typeform.com/to/UPfThS

Moving forward: The new QUIP Task Force

The EACTS has established the first QUIP Database Task Force, who met earlier in April this year, to further develop all aspects of the QUIP's database projects. The QUIP Database Task Force is formed of 11 members, each with experience and a strong interest in database and quality improvement initiatives.

The QUIP ACD is now becoming a powerful tool, that will grow in benefit as it grows in data. The more data contributed, the more hospitals will benefit from the database and the reports it provides. For more information or to join the QUIP ACD, please visit the QUIP website at www.eacts.org/quip or contact the QUIP team at QUIP@eacts.co.uk

Behind the scenes

Meet the team behind the EACTS Quality Improvement Programme

he Quality Improvement Programme (QUIP) team, based at EACTS House in Windsor, UK, and the University Hospitals Birmingham (UHB), UK, work together to promote the aims of the QUIP: to improve clinical outcomes for patients and integrate quality improvement initiatives. The QUIP team at UHB use their technical expertise to ensure the smooth running of the Adult Cardiac Database (ACD), and work closely with contributing centres to ensure that their data is successfully implemented in the database. The project development team at EACTS House lead the recruitment of centres to join the ACD, facilitating communication and leading the strategy to advance the QUIP's aims.



Domenico Pagano EACTS QUIP Chair, University Hospitals Birmingham, UK

Domenico is the EACTS QUIP Chair and Director of the Quality and Outcomes Research Unit (QuORU) at UHB, UK. Domenico provides clinical leadership, builds collaborative relationships with contributing centres and national societies, and leads the strategy developments of the EACTS QUIP project at all levels.



Giacomo Bortolussi Fellow, University Hospitals Birmingham, UK

Giacomo is a Cardiac Surgery Fellow currently

working at UHB, with expertise in large databases and datasets management. Giacomo's role within the QUIP is to provide clinical support for the adult benchmarking project.



Theo de By QUIP Project Manager, EACTS, Windsor, UK

Theo is the first contact for all EACTS members who wish to join QUIP, and actively recruits those who are potentially interested to participate in the benchmarking tool. He informs the members and representatives of their organisations about the various aspects of the engagement process, the QUIP Charter, and the relationship between the EACTS and UHB, UK. Theo interacts with Hina and Simon when registered participants are ready to commence submitting their data into the QUIP ACD.



Hina Waheed Statistical Intelligence Analyst, University Hospitals Birmingham, UK

As part of the QUIP team at UHB, Hina takes the lead role in maintaining the ACD and the benchmarking tool. She is responsible for providing technical assistance and engages with new and existing centres from data mapping stage until their data is in the database. She is the first point of contact for the participating centres and assists users with accessing the benchmarking tool. As the project develops further, she will also be responsible for providing statistical insight.



Simon Baldwin Information Analyst, University Hospitals Birmingham, UK

Simon's main role in the QUIP comprises of ensuring the smooth day-to-day running of the ACD tool, including web development and the analytical functions of the tool, such as the calculation of completion rates and EuroSCORE. He is also responsible for expanding the QUIP web-based tools, under clinical direction; most recently, this has resulted in the development of an ACD demo tool. When Simon is not working on the tool, he works on data quality alongside the clinical and statistical leads to ensure that data is interpreted and represented as accurately as possible.



Stephanie Halksworth QUIP Coordinator, EACTS, Windsor, UK

As the QUIP Coordinator at EACTS, Stephanie coordinates the logistics for the QUIP project. Through implementing shared platforms, Stephanie's role is to enable the different domains of the QUIP project to work in collaboration, ensuring cooperation between recruitment, and the QUIP teams at UHB and EACTS. Stephanie is leading the QUIP marketing strategy and manages the QUIP Task Force.



A SWEDEHEART to heart with QUIP

SWEDEHEART Connects to the EACTS Quality Improvement Programme Adult Cardiac Database

Örjan Friberg

Örebro University Hospital, Sweden **Theo de By**

QUIP Project Manager, EACTS, Windsor, UK

ecently, it was decided that the Swedish Heart Registry (known as SWEDEHEART), will provide data to the EACTS international Quality Improvement Programme (QUIP) Adult Cardiac Database (ACD). In this article, we introduce you to a unique national registry that has covered all procedures in Sweden since 1992. The contribution of Swedish data is considered to be an extremely valuable contribution to the EACTS QUIP ACD.

The purpose of SWEDEHEART

The primary purpose of SWEDEHEART is to support development of evidencebased therapy in acute and chronic coronary artery disease, in catheterbased or surgical valve intervention and genetic heart diseases, by providing continuous information on patient care needs, treatments and treatment outcomes. The aim of SWEDEHEART is also to register changes in the quality and content of patient care over time within a hospital and compared with other hospitals, to contribute to risk prediction tools and decision support, and to support continuous improvement efforts in all participating units.

SWEDEHEART is intended to form the basis for research on coronary artery disease, valve intervention and genetic heart disease. The long-term aim is to contribute to reduced mortality and morbidity in patients, and to improve the cost-effectiveness of patient care.



In addition, SWEDEHEART is a procedure-related and surgery-related registry, for the purpose of collecting relevant information concerning severity of disease, patients' risk profile, medical and medical-device treatment, outcomes, and any complications from the time of intervention for all procedures and surgical interventions performed. Comparisons can be made between hospitals and between regions. The individual operator can also compare his or her results with an average for other operators in the hospital department or in the whole of Sweden. New medical devices can be quickly evaluated, as can different treatment strategies, to provide both short- and long-term perspectives. In the registry, information

is collected from all hospitals that care for patients with acute coronary artery disease, and all patients who undergo coronary angiography, catheter-based intervention, or heart surgery, and reflects an unselected population. The possibility of merging the SWEDEHEART database with other international registries, such as the QUIP ACD, offers complete followup in regards to MI, death and other diseases. In addition, the registry offers the possibility of randomised registry studies of unselected patients. The work of SWEDEHEART therefore represents an important foundation for research into heart disease and has resulted in several publications in highly regarded medical journals. Consequently this has influenced the care of heart disease around the world.

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Data submission methods

Data are either entered directly into the registry online via the internet or exported into the registry from local databases at some of the centres. Completeness of individual variables is high.

Mortality data are derived from the Swedish National Population Registry and are therefore considered 100% complete and accurate. A patient may be operated on more than once, however, mortality figures are presented per individual patient, not per operation. All other data except mortality are shown as reported by the individual centres. Previously no external adjudication of the reported data from each centre has been conducted. However, in 2016 a programme for regular external monitoring and adjudication of registry data with site visits at each centre was initiated.

Results and comments

Based on the national statistics of SWEDEHEART, the Swedish National Board of Health and Welfare have recently highlighted the improper differences in coronary artery bypass graft (CABG) volumes, between different regions and counties in Sweden. In 2015, the Board released its National Recommendations on Cardiac Care pinpointing the improper differences regarding indications for CABG among their central recommendations. Nevertheless, during 2016 no clear trend towards a reduction in the contrasts between counties can be detected in registry data. Regarding outcomes, mortality, or postoperative complications, the differences between the centres are mostly small. The differences in mortality generally vary from year to year in an apparently random way. Adjustment for case-mix with EuroSCORE II has deliberately not been carried out. There are unexplained differences in some of the variables between the centres and since neither EuroSCORE II variables nor reported complications have been previously externally validated and/or adjudicated, risk-adjusted data cannot be considered valid. Too much emphasis on the ranking of centres, could encourage a bias of definitions when reporting data on some subjective riskvariables or outcomes.'It also impedes a sincere and honest cooperation and benchmarking between the centres, which is the most important thing, not only for the registry but for the quality of cardiac surgery across the country.

Advantages of connecting SWEDEHEART to the QUIP ACD

From a national point of view, the advantages for individual hospitals in Sweden is threefold:

- The QUIP offers the ability to benchmark local data on a supranational (European) level, which puts outcomes in a larger perspective.
- The QUIP tool provides unique possibilities to generate, near real-time, statistics using multiple filters to focus on and benchmark specific data. Additionally, data from the benchmarking tool facilitate decision making with respect to individual patients.
- As members of the EACTS, sharing local and national data with colleagues will enable improvements for the entire profession.

The number of European hospitals participating in the QUIP project is now at 66, and increasing. The high quality of data from SWEDEHEART will further add to the power of the QUIP ACD.

Data collection and data quality

Variables	Gothen- burg (%)	Kariskrona (%)	Linköping (%)	Lund (%)	Stockholm (%)	Umeā (%)	Uppsala (%)	Örebro (%)
Clinical demographics	99.91	99.61	99.86	63.91	100.00	100,00	99.53	100.00
EuroSCORE II	100.00	100.00	100.00	100.00	100.00	100.00	99.69	100.00
Procedure code*	100.00	97.27	100.00	100.00	100.00	100.00	100.00	99.75
Diagnosis code*	100.00	99.22	100.00	98.56	100.00	100.00	100.00	100.00
Complications	100.00	100.00	100.00	30.06	100.00	99.55	99.52	100.00
Lab values**	99.25	99.61	99.29	64.00	99.89	99.11	96.80	98.77
Pharmaceutical treatment	99.81	100.00	100.00	100.00	100.00	98.81	99.84	98.77
Date of discharge***	99.82	100.00	100.00	95.50	100.00	99.85	99.84	98.77

A minimum of one code (according to ICD10).

The registry covers all centres that are performing or have been performing cardiac surgery in Sweden since 1992 resulting in 100% coverage regarding the number of adult heart surgery procedures in 2015 (Table 1). The number of cardiac surgery interventions averages at +6000 per year since 2005.

Table 1. Completeness of selected key variables, per centre, 2015.

As shown, the completeness of data is exceptionally high, with the exception of postoperative complications from Lund. This single lower figure is due to a mismatch between the local quality registry in Lund and the SWEDEHEART registry regarding some minor complications, which causes an incomplete data export.



^{**} Lab values here include preoperative haemoglobin, pre- and postoperative creatinine. Only in patients discharged alive.

^{***} Percentage of patients discharged alive.

Spotlight on Spain





Dr Rafael SádabaHospital of Navarra, Spain **Carlos Velasco**Complejo Hospitalario Universitario of A Coruña

pain has excelled this year in their contribution to the EACTS Quality Improvement Programme (QUIP). Spanish centres have joined forces, with the cooperation of the SECTCV (Sociedad Española de Cirugía Torácica-Cardiovascular), and are contributing data to the EACTS QUIP Adult Cardiac Database (ACD). This is known locally as QUIP Spain.

"The feedback has been very positive... I see QUIP Spain progressing quickly to become the 'National registry'"

All contributing hospitals send their cardiac surgical dataset to the Spanish QUIP Registry, and from there, individual hospital data are forwarded to the EACTS QUIP ACD in Birmingham, UK. In January 2016, the Spanish QUIP Registry, located at the Hospital University A Coruña, Spain, was established and a team of surgeons and a data manager oversee the process. The contributing units can now make use of the EACTS QUIP resources for benchmarking purposes and research on an international scale.

This is a leading example of centres cooperating on a national basis and contributing to a supranational database, with consistent and accurate data. An annual meeting in Madrid, organised by the SECTCV for Spanish cardiac surgical units, was held in January of this year to review the Spanish QUIP Registry.

Rafael Sádaba and Carlos Velasco play a key role in QUIP Spain, and have agreed to a special EACTS interview to shed light on Spain's experience in the last year since joining QUIP, and unveil future plans of turning the QUIP into a national registry for Spain...

What is the EACTS QUIP ACD and how did Spain get involved?

Rafa: In Spain, the EACTS QUIP database or QUIP Spain as it is known locally, has been proposed to become the Spanish national registry. It will take the place of the traditional national registry, which has been in operation for over 30 years. The involvement was by serendipity. The Spanish Society of Thoracic-Cardiovascular Surgery decided to develop a patientbased registry some years ago and it was working towards creating it. It was in this context that it was suggested, instead of developing a whole new database, we could take advantage of joining the European registry, which had recently been designed and developed by the Quality and Outcomes Research Unit (QuORU) in Birmingham, UK, a centre of excellence in these matters.

What is your current role in the QUIP ACD?

Carlos: In January 2016, the SECTCV started QUIP Spain with the aim of developing a national database fully compatible and containing all the variables of the EACTS QUIP ACD. All the hospitals in Spain performing cardiac surgery were invited to join to this project. This national database works as an intermediate step to collect, validate and analyse the data before it is sent to the EACTS QUIP database. My task, working along with Rafa Sádaba, Jose Joaquin Cuenca Castillo (Past-President of the SECTCV), Pedro Lima and Cristina Quiñones (data manager of the QUIP project in Spain), has been to develop this national database, defining the recommended variables to include and to give assistance to all the cardiac surgery departments in Spain in the task of sending their data to QUIP Spain.

Since the launch of the SECTCV contribution to the QUIP ACD in January 2016, how many hospitals have signed up?

Carlos: The EACTS QUIP ACD has been very well accepted by the different cardiac surgery departments. So far **27 hospitals** have signed up to QUIP Spain and to date 19 departments have already sent their data to the EACTS QUIP ACD, representing many of the largest cardiac surgery departments in Spain. The remaining hospitals that have not yet signed up are expected to become part of the project within the next year.

What benefits are there to joining the QUIP ACD?

Rafa: I see three significant benefits:

- Allows for benchmarking against other European centres, permitting hospitals to identify areas of strength and weakness.
- Allows those sending data to the QUIP, to use the database to carry out studies and research.
- 3. Access to the clinical support tool, which allows you to find statistics for a population matching a specific criteria.

Carlos: The QUIP ACD gives the cardiac departments the opportunity of benchmarking their outcomes with other hospitals in Europe, identify areas of improvement and share data among different groups.



"I must say, both support teams in Birmingham and at the Hospital A Coruña have done a fantastic job."

Were there any difficulties at first matching the centres' database to the OUIP ACD?

Rafa: There were indeed some difficulties. For starters, there was the language barrier (Spanish vs English). Different centres had different local databases, and often, items in those databases were not matched against QUIP, or the variables and outcomes were measured with different metrics.

How were they overcome?

Rafa: We liaised closely with the support team in Birmingham for the translation of all the items in the QUIP dataset into Spanish. This dataset was then adopted by the centres contributing to QUIP Spain in close collaboration with the QUIP Spain team at A Coruña. I must say that both support teams in Birmingham and A Coruña have done a fantastic job.

The QUIP ACD is more than just a registry – it has beneficial features, including a benchmarking tool, data analysis, and a clinical support tool.

How much do centres use the OUIP tools?

Rafa: I think all that the QUIP ACD offers is the great unknown in the registry. In a recent meeting in Madrid to discuss



the QUIP, it was clear that the message had not got through and most centres had not used it enough. More effort is needed to spread the word of its capabilities and make it more user-friendly.

Spain has progressed enormously in the past year with the QUIP, contributing 19.47% of the data currently in the ACD.

"Joining the QUIP Project is really easy thanks to the invaluable help of the QUIP team"

Why, in your opinion, has QUIP taken off so well in Spain?

Carlos: The SECTCV has always been very concerned about the necessity of analysing the outcomes of the national

cardiac surgery departments to achieve best clinical practice, and has adopted the QUIP project as its own, leading the developing of the new national database (QUIP Spain) on the basis of the EACTS QUIP project. This has facilitated the access to the QUIP for hospitals across Spain.

"All hospitals agreed on the importance of the information obtained with the QUIP Tool and the simplicity of its use"

An annual meeting organised by the SECTCV in Madrid, Spain, took place with the Spanish surgical units. What was the overall feedback regarding the QUIP tool?

Carlos: At the SECTCV annual meeting we received very good feedback from the hospitals sending their data to the QUIP ACD. All the hospitals agreed on the importance of the information obtained with the QUIP tool and the simplicity of its use. Moreover, the delegates of the registry from each department emphasised the good assistance and quick response by the QUIP team to any problems or doubts they experienced.

Rafa: The feedback has been very positive. A large proportion of centres have signed the agreement to join the QUIP and are preparing their databases to submit data in the near future. One of the difficulties identified was the problems that some IT departments were finding to introduce a new database in the centre.

How do you see the progression of QUIP in Spain's future?

Rafa: I see QUIP Spain progressing quickly over the next 2 years to becoming the 'national registry'. For this to happen, all centres must get their databases in line with the QUIP dataset.

Carlos: For sure the remaining hospitals that have still not joined the QUIP project will join in the coming months. The quick and progressive acceptance of the QUIP project in Spain suggests that this project will become the national database within the next 2 years.

What advice would you give to centres in other countries thinking about joining the QUIP?

Carlos: The QUIP ACD is a very effective instrument for benchmarking our outcomes and is much more powerful the more hospitals join the project, so we encourage all the cardiac surgery departments concerned with the importance of achieveing best clinical practice and the best outcomes to join to the QUIP project.

Joining this project is really easy thanks to the invaluable help of the QUIP team who guide you through the process. Joining the QUIP ACD as a country has the additional advantage of developing a national database available for further research.

The main problem we have found joining the QUIP has been to adapt our variables to the QUIP variables, since the categories were not exactly the same. Nevertheless, only minor changes were needed since the mandatory and highly recommended variables did not differ much for the common categories used for estimating risks with the most used risk scores, and thus these variables and categories are common within the current databases. Rafa: Joining the QUIP, either as an individual centre or as a nation, has many advantages as already discussed. Adapting an existing database to the QUIP dataset can take time and effort in the beginning, but any problems may be easily overcome by liaising closely with the QUIP support team.





EUROMACS Longitudinal analysis module: Kaplan Meier function

Theo de By

QUIP Project Manager, EACTS, Windsor, UK

ecently, a Kaplan-Meier module has been added to the EUROMACS Database. To enable the participating hospitals to analyse their data they can make a data download by pressing the "export my data" button after login. This will usually take 2-3 minutes. Traditionally, participants could use these downloaded data to import them in any statistical program. Now, a

new green button "Kaplan-Meier Curves" has been added. This button gives you access to the module.

The Kaplan-Meier module has been



designed to let you create longitudinal analyses as both event-free or survival curves according to a set of calculation rules. The software will let you create a unique group of patients upon which the analysis will be based. You can then select a failure event and the software will then calculate and display a Kaplan-Meier table and curve. A manual, describing step by step how to operate the module can be downloaded by pressing the "dicuments" button.

The EUROMACS development roadmap includes the capacity to create and run multiple curves simultaneously so that for a given grouping variable, multiple Kaplan Meier curves can be created and compared.



Example screen showing how to select for what failure cause you want to make a longitudinal analysis.

Please note that the Longitudinal Analysis module currently displays best in the Google Chrome browser: the plan is to make the module fully cross-browser compatible in the next few months.

EUROMACS update

Dear Colleagues and friends...



Jan Gummert Director, Clinic for Thoracic and Cardiovascular Surgery Heart and Diabetes Centre NRW, Bad Oeynhausen, Germany.

he year 2017 marks a new chapter for the EUROMACS Registry as it relocates to EACTS House in Windsor, UK. This follows the decision by members at the last EUMS meeting on 2 November 2016 that the existing EUROMACS Association had become obsolete, Since 2013, EUROMACS has functioned as a Committee of the EACTS and it will continue to do so. The members of the outgoing board of the EUROMACS Association will remain in place, and for the hospitals that provide the data, nothing will change as the EACTS takes over all obligations associated with the Registry.

On behalf of the EUROMACS Committee, I would like to express my firm gratitude to all those who set up the Association, with special thanks to Professor Hetzer, who remains our Honorary Chairman. Without his efforts, the Registry wouldn't have developed in the way it has during the past 5 years. The Committee is also grateful for the generous grant received from of the Friede Springer Herzstiftung, which enabled the inception of the Association, covered the cost of creating the present database, and provided the funds necessary to develop the network of cooperating hospitals we have today. Within the EACTS, EUROMACS is embedded in the Quality Improvement Programme (QUIP) focusing on benchmarking of outcomes between hospitals. QUIP enables the provision of data to clinicians and researchers. In the near future, new software will enable the EUROMACS community to access statistics and state-of-the-art benchmarking tools.

To all members and clinicians who contribute to the EUROMACS Registry, I express my gratitude for your continuing commitment. Thanks to your efforts and dedication, several colleagues and scientists have been able to use data from the Registry to assist their studies, several of which have been published in the past 2 years. With the increasing number of participating hospitals (now more than 50) and with the application of data audits, a solid basis for scientific, as well as benchmarking, purposes has been created.

Looking to the future, I am convinced that the EUROMACS Registry, together with the increasing number of participants, will be able to grow and further develop its tools to carry out data analyses and to provide insight into the factors influencing the results of mechanical circulatory support.

With warm regards,

Jan.

The EUROMACS Registry, first lustrum accomplishments

fter a period of programming and organisational structuring, the EUROMACS registry went 'live' in April 2012. Initially starting with 7 centres in 5 countries, the registry now has 52 signed agreements with contributing hospitals in 18 countries, while 10 additional institutions are in the process of joining. In several countries, such as France and Italy, the option for all hospitals implanting mechanical circulatory support (MCS) devices to join collectively is being discussed. During this period >3,300 implantations (including 178 in children) of long-term assist devices and >12,500 follow-up records have been registered. The first Annual Report was published in 2015,1 the second report was submitted in February 2017.

Data for scientific research

From 2011 to 2017, data have been provided for the following studies:

- Impact of atrial fibrillation on pump thrombosis and thromboembolic events in long-term left ventricular assist device therapy
- Clinical and echocardiographical feature of right ventricular failure*
- 3. Infectious disease study mid-term MCS study
- 4. Mid-term mechanical circulatory support: comparison of single-centre data with the EUROMACS registry²
- 5. Isolated RVAD implantation study³
- Gender differences in hemodynamics, adverse events and their association with survival in patients undergoing ventricular assist device implantation: insights from the EUROMACS registry*
- 7. International weaning study
- 8. Incidence of thrombo-embolic events⁴
- Demography and outcome data of the Bern VAD-Program retrieved from the Euromacs registry⁵
- Derivation and validation of a novel right heart failure risk score in patients receiving continuous flow left ventricular assist devices: analysis of the EUROMACS registry*
- 11. European results with biventricular support (Inselspital, Bern).

7 centres in 5 countries

ACCOMPLISHMENT

After a period of programming and organisational structuring, the EUROMACS registry went 'live' in April 2012. Initially starting with 7 centres in 5 countries



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ACCOMPLISHMENT

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3,300 implantations and 12,500 records

ACCOMPLISHMENT

During this period >3,300 implantations (including 178 in children) of long-term assist devices and >12,500 follow-up records have been registered



Statistical tools in development

The EUROMACS database software enables every contributor to download the own base-line and follow-up data at any time. These downloads come in a spreadsheet and enable them to make their own statistics, e.g. by means of statistical software.

Recently, a tool has been developed that will enable EUROMACS participants to see unadjusted Kaplan–Meier survival curves of their chosen selection. This further amplifies the importance of having a complete dataset as missing data will have an impact on the analysis. Ventricular assist device (VAD) implantations are excluded from the Kaplan–Meier analysis if, within a period of 30 days after implantation, no follow-up has been entered.

IMACS Cooperation

At the end of 2013, EUROMACS and IMACS agreed to cooperate. While EUROMACS gathers data from those countries on the European continent, IMACS receives data on a global scale. Within this cooperation, EUROMACS provides anonymous data from its registry. This contribution, as well as the contribution of data from other regions, such as North America, Japan, South East Asia and Australia, has enabled the IMACS organisation to publish its first report in 2016.6

*Publications in preparation. The data collected in the registry is also available to members to aid them in policy making, and preparing non-clinical papers or presentations.

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