

**Minutes of the 1<sup>st</sup> Working Group Meeting  
of COST Action CA18118  
“Implementation Research Network in Stroke Care Quality (IRENE)”  
September 16 and 17 2019, Chisinau, Moldova**

**1. Meeting of Working Group 1 – Leadership**

The overall objective of Working Group 1 – Leadership (WG 1) is to provide scientific leadership to participating countries, develop and manage the network, consociate members, accelerate knowledge exchange and establish solid stroke care leadership in participating countries with a special focus on ITC’s.

The content of the activities of WG 1 is directly linked to the scientific activities and submitted research proposals discussed during the Management Committee meeting. For detailed information about the Action’s scientific planning please consult the minutes of the 2<sup>nd</sup> Management Committee meeting.

Ms Luzia Balmer presented the Stroke Action Plan for Europe (SAP-E) on behalf of the SAP-E Implementation Committee and explained the main domains of the document including the four overarching targets. The Action Chair emphasized the need to align the activities of the IRENE COST Action with the Action Plan where possible, with an option to organize a meeting on registries across Europe to discuss what exactly is needed to harmonize these fields.

Task distribution of Working Group 1:

- **Organization of Training Schools:** 1st Grant Period – **Dr. Wagner**; 2nd grant period (= May 2020 – April 2021; **Dr de Miquel?**).
- **Organization of STSM:** **STSM host institution** in cooperation with WG 1 members and the STSM Coordinator.
- **Organization of ITC Conference Grants:** ITC CG Coordinator in cooperation with WG 1 members.
- **Methodology support to Country Coordinators and to young scientists** = providing support in writing papers and implementation of a quality measurement strategy: **this will be distributed based on specific topics and countries.**
- **New scientific topics + papers** (distribution, organization of the work on research proposals): **participants, who submitted a research proposal** in cooperation with **WG 1 members.**

**2. Meeting of Working Group 2 – IRENE COST Action Members**

The overall objective of Working Group 2 – IRENE COST Action Members (WG 2), is to provide an evidence on stroke care quality in all involved ITC’s through the coordination of data collection and the provision of a web-based registry.

The Leader of WG 2, Prof Cristina Tiu, presented the successful story of establishing stroke centers in Romania, which lead to improving the overall stroke care quality in the country. Prof Tiu also provided recommendations for the participants on how to be successful in measuring and improving stroke care based on the Romanian experience. The presentation by Prof Tiu is an example of best practice and should be an inspiration to countries, where stroke centers are not established and the overall stroke care lacking in quality.

The following steps presented by Prof Tiu should serve as a “guide” to other participating COST countries in establishing solid stroke care quality in their countries:

- 1) Establishing a National Steering Committee with key opinion leaders in the country
- 2) Collecting data into the Registry of Stroke Care Quality (RES-Q)
- 3) Involving national governments and health authorities

Prof Tiu further outlined the next steps for Romania, which are mainly related to increasing the number of centers collecting stroke care quality data, publishing results of the data analysis in scientific papers and further striving to improve the quality of stroke care in Romania.

The Action Chair asked how can be the IRENE COST Action of help in supporting the establishment of an improved stroke care quality in participating countries. Prof Tiu stated that the existence and further development of the RES-Q registry is crucial for countries, which are striving to improve their stroke care quality. Furthermore STSM’s and Training Schools can be a helpful tool to accelerate the process and obtain important know-how from countries, which are more experienced in certain areas of stroke care.

Ms Svobodova strongly emphasized the importance of creating country-specific reports containing the current state of stroke care quality in those countries, where collected data are representative. The printed reports, which should be dedicated for communication to stakeholders on stroke care improvement, are an eligible expenditure and can be funded from the budget of the IRENE COST Action. Furthermore, the Leader of Working Group 3, Ms Andreea Grecu, can provide the needed country-specific data from the RES-Q registry to the participants.

### **3. Meeting of Working Group 3 – Registry Management**

The Leader of Working Group 3 – Registry Management (WG 3), Ms Andreea Grecu, and her colleague Mr Steven Simsic explained the main objectives, tasks and deliverables of WG 3 and presented specific deliverables, which were already achieved in the IRENE COST Action’s lifetime. Furthermore, Ms Grecu introduced the Register for Stroke Care Quality RES-Q and explained the main ideas behind it. Mr Simsic continued by outlining the progress of RES-Q during time – from collecting data to their thorough and flexible analysis. Mr Simsic emphasized that collecting data is not enough, they have to be meaningfully interpreted in order to make a difference. Ms Simsic further showed to participants the basic RES-Q form and reminded that the form can be adapted to each country according to their individual needs.

Ms Grecu shared with participants the up-to-date RES-Q information – currently, there are 60 countries enrolled with over 120 000 patients. Ms Grecu further stressed the benefits of the website, which is updated hourly and encouraged the participants to download reports directly from the website, as this can be a useful tool for conferences, scientific papers or national reports.

Mr Simsic continued with outlining the next big project of RES-Q, which is a large imaging database. Mr Simsic further commented on data policy and current challenges RES-Q is facing in this area, mainly

with regards to GDPR and data validity. Ms Simsic emphasized the importance of transparency and fairness and stated that all policies are available directly on the RES-Q website ([www.qualityregistry.eu](http://www.qualityregistry.eu)). Ms Grecu added that RES-Q is currently working on getting the data and the meaning of collecting it to nurses in a more efficient way. Ms Grecu also mentioned the idea to incorporate a mobile application in addition to the website, as some hospitals do not have enough resources for computers.

Dr Markus Wagner raised a question concerning the access to the imaging database and the consent of patients to use the images. Mr Simsic stated that in order to access data for people outside of RES-Q, a submission of a research proposal and a justification will be needed. This will be then approved by a Steering Committee. As of now, the most important question is to demonstrate that the collection of images directly leads to improving the stroke care quality, which is an ongoing discussion.

### Task distribution of Working Group 3

- 1) **Data Analysis:** Review of currently generated national and site-level reports, as well as other resources such as the live dashboards, including the currently used descriptive statistics calculations
  - Review: **Dr Michal Karlinski/other clinician**
  - Implementation: **RES-Q core**
- 2) **Collection of feedback on whether the registry fulfils user needs**, suggestions for improvement
  - Reporting form made available, yearly user feedback questionnaire: **RES-Q core**
  - Feedback collection supported by **a national representative** in the particular country
  - Feedback review by **Dr Michal Karlinski/Dr Janika Körv/Dr Hendrik Knoche**
- 3) **Collection of feedback on Reports and Dashboards** (follow-up from task 1), targeting power-users (i.e. users that use RES-Q tools consistently)
  - Feedback collection and synthesis – supported by **national representatives, Dr Michal Karlinski/Dr Janika Körv/Dr Hendrik Knoche**
  - Extension to RES-Q platform to enable usage collection (who logs in, what is downloaded), implementation of changes: **RES-Q core**
- 4) **Quality Assurance and Control** (for RES-Q outputs): **clinicians** (to review and set measurement criteria) + **RES-Q core** (to implement approved changes)
- 5) **Data Quality Standard** (for collected data)
  - Methodology for QA and QC – does the data we have match the hospital’s records and is it representative of the population / healthcare system?
  - Measurement of data quality established (**clinicians + RES-Q core** for baseline) and implemented (**RES-Q team** and **clinicians** for review)
- 6) **Evaluate the registry’s alignment to the current GDPR best practices**, including collection of outcome data: **Mr Steven Simsic + lawyer**
- 7) **Data Dictionary:** updated for the RES-Q 2.0 and comprehensive protocols – initial draft: **Ms Nina Chufarova**, review by **selected clinician representatives**

- 8) **Harmonizing registries** within IRENE COST countries = same metrics in different registries (**Diana de Sousa**)
- 9) Data import and analysis from **non-RES-Q sources**, e.g. national registries, SITS: **national representatives, i.e. Prof Gdovina** for Slovakia, **RES-Q core** for implementation.
- 10) **Involvement of representatives** of national/other registries (**Prof Robert Mikulik, Prof Urs Fischer, Dr Francesca R. Pezzella, Dr Markus Wagner, Dr Diana de Sousa, Ms Luzia Balmer**).
- 11) **Organizing meetings/symposia** on registries with the goal of:
  - mapping
  - harmonizing
  - sharing knowledge

Participants in charge of organizing meetings/symposia: **Prof Robert Mikulik, Prof Urs Fischer, Dr Francesca R. Pezzella, Dr Markus Wagner, Dr Diana de Sousa, Ms Luzia Balmer**. The specific place and organiser will be defined later.

The Action Vice-Chair stressed that national registries should be prioritized before hospital registries. There is a clear need of developing a mechanism, through which national governments/ministries of health can be effectively approached to implement national registries.

Dr Francesca R. Pezzella shared her experience from Italy, where registries are mandatory (not national registries, but SITS) and stressed the need of developing a culture of advising those that need to be advised and offering tools for them. The key players should be national societies in each country and IRENE could be a tool to facilitate the entire process.

#### **4. Meeting of Working Group 4 – Dissemination**

The overall objective of Working Group 4 (WG 4) is to enhance the impact of the IRENE COST Action through the involvement of diverse stakeholders, information activities targeted at stroke professionals and stakeholders in other geographical areas and campaigns to motivate professionals in other medical fields to follow the IRENE COST Action's results. WG 4 aims to inform the lay public about stroke risks and stroke care, in order to increase their awareness and potential interest to be involved in the implementation process.

The Leader of WG 4, Dr Milan Vosko, introduced the Vice-Leader, Prof Anita Arsovska and outlined the main goals and outputs of the meeting. Dr Vosko continued with reminding the participants of the main objectives, tasks, milestones and deliverables of WG 4.

##### Task distribution of Working Group 4:

- **Logo creation:** The order of the service managed by the Grant Holder (St. Anne's University Hospital Brno)
- **Website creation:**
  - The order of the service managed by the **Grant Holder** (St. Anne's University Hospital Brno)
  - Structure of the website: **Ms Jennifer Thomsen**
  - Content: **all WG 4 members**

- Maintenance/update of the website during the project: **Ms Julia Dankova**
- **Social media** (LinkedIn and Twitter): **Dr Hrvoje Budincevic** in cooperation with **Mr Fabrizio Pennacchi, Ms Jennifer Thomsen, Prof Derya Uludüz, Prof Anita Arsovska**. The goal is to have ideally one person per channel.
- **Development of Communication Strategy and Dissemination Plan:** **Mr Fabrizio Pennacchi, Dr Markus Wagner, Prof Derya Uludüz, Prof Vitalie Lisnic, Dr Ivan Miskulin, Mr Kyle Cilia, Dr Hrvoje Budincevic**
- **PR articles** in journals and newsletters on the Action's progress: **all WG 4 members**
- **Annual summary brochures** with results from the registry: **ANGELS Representatives + representatives from ITC's**

The Science Communication Manager, Dr Francesca R. Pezzella, will be informed of new outputs through the IRENE COST Dropbox folder, where participants are able to upload any relevant output, which can be disseminated.

Mr Pennacchi raised the question regarding the communication at national levels. Dr Vosko stated that this area remains in discussion, as it is currently not possible to say who exactly will be responsible for PR related activities and the dissemination of results in participating countries. Mr Pennacchi was further interested in the cross-linking options, to which Dr Vosko reacted that cross-linking and thus increasing the Action's visibility and collaboration is crucial and will be strongly encouraged during the Action's lifetime.

Dr Vosko suggested to use one e-mail for WG 4 purposes and to incorporate a blog on the IRENE COST website, in order to foster interaction, to which the participants agreed. Dr Pezzella added that in order to keep the interest on a high level, frequent updates on both the blog and website are needed.

Mr Pennacchi and Dr Budincevic discussed the visibility of the Action through tags and hashtags. Mr Pennacchi suggested to use an effective tag (for example on LinkedIn), which will reflect the Action's focus (stroke care quality) and which will mention the name of the Action. Dr Budincevic suggested to use the hashtag #IRENECOST on social media.

Dr Knoche addressed the important issue of internal communication with Action's participants. Online management tools, such as BaseCamp, Freedcamp and Slack were mentioned – Dr Knoche will look into the best option and suggest it to the Action Chair and Action Manager.

## 5. Tour de table: Specific contribution of participants to the IRENE COST Action

- **Ms Andreea Grecu:** leadership and coordination of Working Group 3; participation in a STSM focused on registries.
- **Dr Francesca Romana Pezzella:** establishing the communication tools in order to deliver the objectives of the Action's dissemination; close cooperation with WG 4; understanding possible synergies with SAP-E; regular updates to the COST Science and Administrative Officers about PR and dissemination activities; participation in the COST Workshop for Science Communication Managers.

- **Mr Fabrizio Pennacchi:** cooperation with Dr Wagner and Dr Knoche with regards to stakeholder communication; participation in the development of the Communication and Dissemination Plan; participation in the COST Workshop for Science Communication Managers.
- **Dr Markus Wagner:** preparation of the Training School for the first Grant Period; assistance in developing the Communication and Dissemination Plan.
- **Dr Dorien Vandenborre:** augmentation and improvement of the submitted research proposal.
- **Mr Axel Kohlmetz:** supporting new research proposals and making sure they are in accordance with SMART criteria; cooperation in improving leadership knowledge and skills for juniors and seniors with a focus on Eastern European countries.
- **Mr Thomas Fischer:** supporting activities with ANGELS in Eastern Europe and striving to get more companies on board (specifically companies focused on thrombectomy); cooperation with ANGELS on national RES-Q brochures.
- **Dr Milan Vosko:** leadership and coordination of WG 4; collection and summary of ideas within WG 4; cooperation on the drafting of the Dissemination and Communication plan (with a focus on the website and social media channels).
- **Prof Birgitta Langhammer:** not yet fully decided on the exact contribution to the Action, but would like to focus more on speech therapy.
- **Dr Zada Pajalic:** focus on increasing professional skills and patient-centred care; work on the submitted research proposal.
- **Dr Hendrik Knoche:** work on the strategy of how to use the Action's limited resources effectively; cooperation with WG 3 and the RES-Q team; management/communication tool suggestion; work on the submitted research proposal.
- **Dr Lina Palaiodimou:** striving to include more hospitals from Greece into the registry (also from rural areas); using RES-Q data for a cost-effectiveness study; addressing the need to increase the number of stroke units in the country to important stakeholders.
- **Dr Victor Becerra-Muñoz:** attended the meeting instead of Dr Jiménez-Navarro; making sure that his hospital participates in RES-Q.
- **Dr M Angels de Miquel:** redefining and refocusing the proposed Training School for the second Grant Period.
- **Dr Francisco Campos:** work on the submitted research proposal.
- **Dr Mihael Tsalta-Mladenov:** working on analysing the data from RES-Q and publishing them; cooperation with WG 3.
- **Prof Derya Uludüz:** communicating the addressed topics, IRENE COST activities and RES-Q to colleagues and important stakeholders in Turkey; possibly submitting a research proposal; actively contributing to WG 4 mainly with regards to PR activities and social media.
- **Prof Anita Arsovska:** preparation of a short meeting report for the ESO blog and newsletter; preparation of a report for the Stroke Alliance for Europe with an emphasis on the Training School for the first Grant Period; possible organisation of a Training School in North Macedonia; using the data from RES-Q to publish a scientific paper (with the resources for the open access fee from the IRENE COST budget).
- **Dr Kyle Cilia:** active involvement in WG 4.
- **Dr Maria Mallia:** applying for the ITC CG; working on the submitted research proposal and on the proposed survey and aligning both to the IRENE COST objectives; participating more actively in ESO.
- **Dr Sarah Craus:** striving for an involvement in the RES-Q registry.
- **Dr Neophytos Stylianou:** cooperation with Prof Tzivian on her research proposal.

- **Dr Janika Kõrv:** discussing a more active and improved involvement in RES-Q with the Steering Committee; possible submission of a research proposal; communicating the IRENE COST activities and networking possibilities to young doctors; designing and publishing brochures using RES-Q data.
- **Dr Aleksandras Vilionskis:** striving to further improve the stroke care quality in Lithuania; writing papers on the current state of stroke care and comparing it to other countries; presenting the implementation strategy at national conferences (and including the implementation plan as a part of the dissemination strategy).
- **Dr Rytis Masiliūnas:** working on the methodology of the submitted research proposal; cooperation with social media in Lithuania.
- **Prof Lilian Tzivian:** establishing a group/task force of participants interested in the submitted research proposal (with a start at the beginning of the year); IRENE COST Action can help in the funding of publication fees.
- **Prof Alexander Tsiskaridze:** disseminating information about the IRENE COST Action and RES-Q with colleagues and important stakeholders; expanding the number of centers participating in RES-Q; working on comparative studies.
- **Dr Nune Yeghiazaryan:** participation on STSM's focusing on data registries; striving for the establishment of a database structure in Armenia (IRENE COST Action could facilitate such establishment); organisation of a Steering Committee meeting in Armenia and advising the Ministry of Health to make registries obligatory in every hospital.
- **Dr Ivan Miskulin:** writing a proposal for a Training School; publishing a paper based on the collected data; active involvement in WG 4 with a focus on social media.
- **Dr Hrvoje Budincevic:** active participation in WG 4 with a focus on social media; cooperation on the paper with Dr Miskulin based on RES-Q results from Croatia.
- **Dr Milan Maretta** (Substitute for Prof Gdovinova): publishing the data collected from the RES-Q registry and using the published data to promote the activities to important stakeholders (i.e. Ministry of Health).
- **Prof Maria Augusta Silva:** participation in the Training School; active participation in WG 4.
- **Ms Nina Chufarova:** preparing annual brochures with RES-Q results and assisting other countries in their preparation (Poland, Ukraine).
- **Dr Michal Karlinski:** working on the improvement of RES-Q and accepting suggestions of further developments to make the registry more user friendly; regularly informing the WG 3 members of updates; drafting a paper on the evolution of stroke care quality based on available RES-Q data (using the IRENE COST open access funding); drafting an abstract for ESOC 2020 and applying for an ITC CG; communication about IRENE COST in national stroke conferences; participation in the Training School.
- **Prof Anna Czlonkowska:** spreading information about IRENE COST to important national stakeholders; cooperation with Dr Karlinski on aforementioned activities.
- **Dr Nataliia Chemer:** presenting RES-Q data on national meetings; creating a brochure based on the collected data (in cooperation with Ms Andreea Grecu, who will provide the data); preparing scientific papers.
- **Prof Cristina Tiu:** communicating the activities of IRENE COST Action on national stroke conferences; promotion of IRENE COST in Romania; using IRENE funding for printing out brochures; preparing a paper on the comparison of all regional stroke care data.
- **Prof Stanislav Groppa:** focusing on social problems facing patients in Moldova and the position of stroke patients in the society; coordinating the preparation of the Moldova research study; promoting IRENE COST activities to important stakeholders.

- **Prof Natan Bornstein:** assisting the Action Chair in the overall coordination; cooperating with the STSM and ITC CG Coordinators; coordinating the preparation of the Moldova research study; encouraging participants to present their national data at international conferences (ESOC).
- **Prof Robert Mikulik:** coordination of the whole Action; cooperation with Working Groups to achieve the overall objectives; at national level: work on publications.
- **Ms Veronika Svobodova:** complete and share the STSM call and STSM guidelines; prepare the guidelines for approving/rejecting STSM application for the Vice-Chair; support WG Leaders in the coordination of activities.

Due to limited time, the specification of participants' tasks including the deadlines was not discussed thoroughly and will be discussed/decided with participants electronically.

## 6. Meeting on the Moldova project

The goal of the meeting on the Moldova project was to develop and conduct a national study on stroke care quality monitoring through using the registry tool.

Representatives from Moldova, Dr Eremei Zota and Dr Elena Manole, introduced the main aspects of the Moldovan stroke care and shared their experience in establishing stroke care services in the country.

The Action Chair congratulated on the achieved success and recommended the next steps to be taken. The first step is to provide a snapshot of the quality of stroke care and the second step is to describe the trends. For example publishing a scientific paper on the number of patients, who receive a CT scan, however, as this is a politically sensitive topic, the data must be presented in a careful way.

Dr Wagner provided suggestions on topics for further scientific papers, such as familiarity with risk factors, which could raise awareness about the area of stroke care. Prof Malkoff, a special guest and advisor from the USA, reminded that educating people about risk factors is important, however, we must avoid advertising treatment without being able to deliver.

The Action Vice-Chair stressed the importance of having an operational manual and regular workshops for each hospital, in order to explain how to work with the registry.

Summary: All the attendees obtained important information on stroke care organization as an input for designing research projects in stroke care quality in Moldova. Attendees will continue in designing the study. Prof Groppa and Prof Bornstein will coordinate the preparation of the study. Representatives from Moldova will use the STSM tool for developing a methodology of the study.

## 7. Closing

The Working Group meetings concluded at 3:30 p.m.



## **List of Annexes**

Annex 1 – Working Group 1 (Leadership)

Annex 2 – Stroke Action Plan for Europe

Annex 3 – Working Group 2 (IRENE COST Action Members)

Annex 4 – The process of stroke care improvement in Romania

Annex 5 – Working Group 3 (Registry Management)

Annex 6 – Quality Monitoring and RES-Q

Annex 7 – Working Group 4 (Dissemination)