

Minutes of the 3rd Management Committee Meeting of COST Action CA18118

“Implementation Research Network in Stroke Care Quality (IRENE)”

March 4 2021, Online

MC Meeting Attendees

Robert Mikulik (CZ), Natan Bornstein (IL), Jera Kruja (AL), Olsi Taka (AL), Milan Vosko (AT), Axel Kohlmetz (AT), Thomas Fischer (AT), Dorien Vandenborre (BE), Mihael Tsalta-Mladenov (BG), Georgios Hadjigeorgiou (CY), Sabina Hladikova (CZ), Jakub Simkovic (CZ), Veronika Svobodova (CZ), Markus Wagner (DE), Hendrik Knoche (DK), Lina Palaiodimou (EL), Francisco Campos Perez (ES), Maria Angeles de Miquel (ES), Juan Sebastian Ruiz Constantino Fernandez (ES), Janika Korv (EE), Riina Vibo (EE), Hrvoje Budincevic (HR), Daniel Bereczki (HU), Valeria Caso (IT), Francesca Romana Pezzella (IT), Fabrizio Pennacchi (IT), Aleksandras Vilionskis (LT), Rytis Masiliūnas (LT), Vitalie Lisnic (MD), Elena Manole (MD), Anita Arsovska (MK), Maria Mallia (MT), Birgitta Langhammer (NO), Zada Pajalic (NO), Michal Karlinski (PL), Diana Aguiar de Sousa (PT), Elena Terecoasa (RO), Cristina Tiu (RO), Inga Dadeshidze (COST), Nune Yeghiazaryan (AM), Nataliia Chemer (UA), Yuriy Flomin (UA), Dmitriy Gulyayev (UA)

1. Welcome to participants and update from Action Chair

Action Chair Prof. Robert Mikulik started off by saying that despite the pandemic IRENE COST Action managed to do quite a lot. In case of IRENE, MC Members are usually top-tier physicians working under heavy workload. He gave the update regarding the scientific portion of the Action. There are 33 countries involved in IRENE, 30 members and 3 Near Neighbour Countries.

IRENE has 2 main Research Objectives: 1) Developing an implementation strategy for stroke care quality measurement in focus countries and 2) Providing an evidence on stroke care quality in all involved inclusiveness target countries through the coordination of data collection and the provision of a web-based registry. IRENE has also its capacity building objectives: 1) to create a solid international network of stroke professionals 2) to interconnect IRENE COST Action network with international bodies and initiatives and 3) to develop tools for increasing professional skills and knowledge of IRENE COST.

There are already three papers published during IRENE’s lifecycle dedicated to IRENE. The first one was the Slovak paper lead by Prof. Zuzana Gdovinova on the impact of COVID-19 on stroke care. The paper on stroke care improvement in the Czech Republic was led by prof. Mikulik and the multinational collaborative paper written by a group of authors led by Prof. Stanislav Groppa and Dr. Elena Manole was already submitted to scientific journal.

Prof. Mikulik updated MC Members about the latest developments in the RES-Q registry. The number of countries involved is now 71, not limited to Europe, while the number of patients surpassed 315 000.

RES-Q has a lot of functionalities that reflect the way the processed data is delivered to healthcare professionals. Prof. Mikulik showed and explained these functionalities, the ability to download them in various formats. Moreover, National Coordinators are allowed to download non-anonymised data that allow them to compare the quality in their countries. As the Czech Stroke Society, we frequently discuss this data with the Ministry of Health, Prof. Mikulik said.

2. Introduction of the support team in Brno

IRENE Co-Founder Veronika Svobodova introduced Ms. Sabina Hladikova, project coordinator, and Mr. Jakub Simkovic, project manager, who will both help with the day-to-day activities of the Action.

3. Verification of the presence of two-thirds of the Participating COST Countries

The verification was successful. 24 out of 30 Participating COST Countries were present.

4. Adoption of the Agenda

The agenda was adopted without any objections to it.

5. Approval of minutes and matters arising during the last MC meeting

The minutes from the previous meeting were displayed and subsequently approved.

6. Election to the management structure

a) MC Member Prof. Valeria Caso (IT) was elected Working Group 1 Leader.

b) MC Member Prof. Hendrik Knoche (DK) was elected Working Group 3 Leader.

c) MC Member Mr. Axel Kohlmetz (AT) was introduced as the Stroke Rehabilitation Improvement Programme Liaison for Eastern Europe for IRENE.

7. Update from Grant Holder and progress report of working groups

Grant Holder Manager Ms. Veronika Svobodova commented on the current state of meeting the Grant Agreement Period Goals for Grant Period 2. The Action is on the right track to meet all the goals by the end of the extended period until 31/10/2021.

Action's deliverables for the 2nd Grant Period are as follows: 1) Implementation strategy for stroke care measurement for Eastern European and Central Asian countries (methodology) 2) Tailored national Implementation Strategy and Stroke Care Quality Action Plan in 80% of inclusiveness target countries 3) 3 Success stories on national or international leadership as a tool of stroke care measurement strategy implementation.

Working Group 1 – Leadership is to launch additional research projects and seeks to provide leadership to scientific papers that are already in the making. The WG 1 deliverables specific to the current Grant Period are already in progress.

Working Group 2 – IRENE COST Action Members had its own separate meeting in November 2020 and continues to work closely with stroke care leaders in Eastern European countries. The stroke care quality data collection is done at least once a year and we are preparing a survey on the way the data is collected according to countries. WG 2 is implementing of the Stroke Action Plan for Europe.

Working Group 3 – Registry Management relies on the operation of the RES-Q registry based in Brno, Czech Republic. Annual data collection is ongoing and data reports are provided to countries involved. Improving data reports based on user experience is a matter of a new project launched in collaboration with Prof. Knoche, MC Member from Aalborg University and the new WG 3 Leader. WG 3 deals with the GDPR issues and for that reason a collaboration with Czech National Center for Cybersecurity was initiated forming the Legal Task Force.

Working Group 4 – Dissemination will now adjust Communication and Dissemination plan according to the feedback of the IRENE Network. Social media account are to start frequent communication and the IRENE website is undergoing minor changes. The gateway to the website could ideally be the IRENE Newsletter. Meeting the deliverables was debated at a separate WGs Meeting the next day.

Dr. Markus Wagner (DE) then commented on the Science Communication Workshop that took place on the 18th of February 2021. More modules of the Workshop tailor made according to feedback will be added soon.

8. Update from the COST Association

COST Science Office Dr. Inga Dadeshidze appreciated the progress IRENE has achieved. Regarding the budget, Dr. Dadeshidze mentioned the possibility to adjust the budget, however the Action does not foresee any on-site event for the time being. She pledged her willingness to approve potential budgetary adjustments.

9. Scientific planning

At the very beginning of the Scientific Planning part, the issue of data sharing was raised. This will be addressed at a separate meeting. Scientific Planning partially rolled over to the next day – the Working Groups Meeting, however, some of the ongoing research projects were debated in detail.

Prof. Natan Bornstein introduced Moldovan project comparing data from RES-Q registry with countries alike (Georgia, Lithuania and Romania) for 3 years. This project could serve as an example for similar projects elsewhere. Dr. Elena Manole added that the paper stemming from the project is being revised. Prof. Valeria Caso subsequently informed about the support for abstracts from Eastern European countries in order to develop full scientific papers.

Prof. Daniel Bereczki reminded MC Members that in November 2019 IRENE leadership suggested to those who proposed their ideas for research proposals to take into account that IRENE can cover only those expenses related to mobility, conferences and publishing. Prof. Bereczki announced that his project idea to evaluate features of stroke care in Hungary, may not have enough data to publish international research papers.

Prof. Zada Pajalic explained her idea behind the ongoing systematic literature review of healthcare technology which is very close to the scope of IRENE COST Action. MC Members were invited to get on board with this activity that aims to combine efforts of 3 different COST Actions. Prof. Pajalic commended the idea that IRENE COST Action would eventually develop an application to Horizon Europe funding and expressed her desire to contribute to IRENE's scientific paper production.

Additional research proposals were discussed the next day at the WGs Meeting and IRENE network is likely to convene again to continue developing these ideas.

10. Location and date of next meeting

Location and date of next meeting will be decided later and announced accordingly, based on epidemiology situation.

11. Summary of MC decisions

Election of Working Group 1 Leader – Prof. Valeria Caso

Election of Working Group 3 Leader – Prof. Hendrik Knoche

Introduction of the *Stroke Rehabilitation Improvement Programme Liaison for Eastern Europe for IRENE* – Mr. Axel Kohlmetz

12. Closing

The 3rd Management Committee meeting concluded at 4 p.m.

Second Day

Albeit some of the mandatory agenda of the Management Meeting was omitted, the second day of the IRENE Meeting was considered a separate meeting and was open to all the MC Members, Ms. Veronika Svobodova explained and introduced the agenda.

The bulk of the IRENE Meeting on the 2nd day consisted of the continuing debate on Scientific planning of IRENE COST Action.

1. Scientific planning

MINERVA software

Dr. Francisco Campos and Juan Sebastian Ruiz (Lincbiotech/ES) presented the MINERVA software, a cloud-based platform that facilitates the processing of CT and MRI images help physicians in the acute phase of stroke (CDSS system for neurological diseases).

Mr. Ruiz explained the current status of development with some of the biomarkers already in the clinical validation phase and others being completed by June 2021. MINERVA's results for CT-perfusion to assess acute ischemic stroke were evaluated with a total of 63 patients. MINERVA results are being compared against the main software in the market RAPID and against 3 popular decision-making softwares in the clinical setting.

Creators of MINERVA are now looking for collaborators to expand validating of their product – to get the feedback and to provide them with retrospective neuroimaging database of patients and access to other stroke software. On the other hand, Lincbiotech offers compensation fees, limited-time free access and collaboration on publications.

Prof. Mikulik suggested that Mr. Ruiz prepares a summarizing material for IRENE COST Action Members and then prepares several separate meeting with members that are interested to team up with them.

Horizon Europe

Prof. Hendrik and Mr. Jakub Simkovic informed about the ongoing initial preparation phase of creating a consortium that would eventually apply for Horizon Europe funding. The call topic in mind for IRENE is *HORIZON-HLTH-2021-TOOL-06-03: Innovative tools for use and re-use of health data*, which is a research and innovation action (RIA).

Simkovic explained that this type of action is entitled to a 100 % funding but each eligible proposal is proposed by a consortium of 3 Horizon Europe member states. There will be 4 projects funded with each of them having approx. 8 million EUR worth of budget.

Prof. Knoche said that European Union is with these projects looking to establish industrial leaders in Europe. Project proposals should aim to improve the quality, machine-readability and re-use of health data. That way the data should become more accessible to clinicians, researchers and citizens.

European Commission is specifically interested in natural language processing tools, semantics and ontologies. Novel solutions based on machine- and deep learning, a decision-support system of sort, should take into account EU legal and ethical requirements. Among the partners that we require to join us in the consortium are experts on GDPR, health records exchange formats, natural language processing, visual assistants and usability for end-users.

Prof. Knoche has already shown a possible arrangement of upcoming Working Groups of such project consortium based on the call text and invited IRENE MC Members to participate either as participants or work package leaders.

Prof. Mikulik noted that the natural language processing tools are already in the development plan for RES-Q - to transfer data from discharge summaries to the registry. Similar multidisciplinary project is already in place in Israel, prof. Bornstein added. To move forward, Stroke Team Brno will share an outline of the project requirements to IRENE network to start brainstorming ideas. Lastly, there are potentially other calls to participate in, however, they may be less compatible with our current scope of work.

Dedicating papers to IRENE

COST Action has its benefits but the purpose of available funding is rather limited, Ms. Svobodova explained. IRENE is a research project and therefore its success is measured in KPIs – Key Performance Indicators. Meeting these could help us improve our reputation and secure future funding.

IRENE can provide financial support such as publication fees to those publications, if the authors are from at least 3 IRENE member countries. Nevertheless, any stroke care quality related paper by IRENE member can be counted as an IRENE COST Action result, if dedicated to IRENE.

Ms. Svobodova then displayed to correct way to dedicate the paper to our Action and singled out the case of paper of Prof. Gdovinova from Slovakia, which was not funded by IRENE, yet it was dedicated to the Action.

The dedication to IRENE itself:

„Supported by the COST (European Cooperation in Science and Technology) Association, Project No. CA18118, IRENE COST Action – Implementation Research Network in Stroke Care Quality.”

and the example provided by Prof. Gdovinova's paper was the following:

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Research proposals, updating the plan

IRENE COST Action members went through the list of project proposals proposed within the network to see if there is a way to enhance the collaboration and get more members to participate in each of these potential projects.

a) Mr. Axel Kohlmetz introduced his idea to extend the **ACURE Program** (Austrian Cooperation Ukraine Rehabilitation) under the umbrella of IRENE network. Physicians and therapists from leading Ukrainian hospitals join Short Scientific Mission in Austria. Owing to this program, 63 rehabilitation physicians and 71 therapists were already trained during 3 trainings in 2020. Similar program is to be launched in Armenia, Azerbaijan, Belarus or Russia. To provide scientific methodology for the project, IRENE invites its members to contact Mr. Kohlmetz.

Based on the presentation, Prof. Georgios Hadjigeorgiou (CY) suggested preparing paper to cover the state of the art in rehabilitation in Eastern European countries. The idea was supported by both Prof. Mikulik and Prof. Bornstein. Prof. Flomin also recommended contacting national societies.

b) Promotional brochures to governments were up next. Prof. Mikulik told MC Members of the reasoning behind this initiative. These brochures can highlight the differences in stroke care in Europe and IRENE will cover the cost of the publication.

Since this is a marketing topic, Axel Kohlmetz and Markus Fischer offered to lend their hand to make it happen. Prof. Valeria Caso and IRENE's Science Communication Manager Dr Francesca R. Pezzella could utilise their experience with advocacy, to visualise the data Prof. Knoche could chip in, Ms. Svobodova noted. Mr. Thomas Fischer said he could offer his backing to this activity.

c) UX of RES-Q Feedback project was presented by the new WG 3 Leader Prof. Hendrik Knoche. He described the workflow of this activity going from reviewing the literature up to the planning of the next steps. Prof. Knoche and his team are aiming to interview the staff from volunteering sites with people who interacted with RES-Q feedback and know how the hospital is doing in terms of stroke care quality. Prof. Knoche's team in Denmark is interested in user stories in context of the hospital, expectations about using RES-Q and key performance parameters.

d) Dr. Maria Angeles de Miquel presented her vision of the upcoming **IRENE Training School (#2)**. Her idea for training school revolves around **Setting Up Urgent Stroke Treatment**. Dr. de Miquel asked MC Members whether the Training School would be more interesting if it covered the whole process or focused more on specific setting in hospital or the thrombectomy itself.

According to Dr. de Miquel, the workshop could start off by reviewing the organisation of stroke care, then break out into various working sessions and then have a concluding session. Prof. Mikulik suggested that Dr. de Miquel should establish who, is the candidate for such training, what is the target audience. He also noted that the reasons for the lack of thrombectomy in countries is due to vastly different reasons. Ms. Svobodova said that the training could be seen as a consultancy how to organise stroke care provided for us by Catalonian experts. Prof. Bornstein suggested modular nature of the training workshops. Mr. Fischer offered his help and to involve Angels Initiative.

2. Budgetary adjustments

Ms. Svobodova revealed the current spending of IRENE COST Action. On-site meetings will not happen, therefore the Action is massively under-spending unable to claim administrative costs. The MC Members can now indicate their needs so that the budget can be adjusted accordingly. The number of Short Term Scientific Missions and Conference Grants could be raised and IRENE invites its members to decide where we should re-route the funds. This Grant Period, the Grant Holder Organisation in Brno was able to claim only 225 EUR for administration.

3. Closing and summary of the plans

Action Vice Chair Prof. Natan Bornstein encouraged MC Members to use the data accumulated during the lifetime of the Action.

Prof. Mikulik summarised the plans:

- a) Grant Holder will share the working document with all the research proposals included.
- b) Thomas Fischer will give MC Members help creating brochures to approach governments.
- c) Horizon Europe proposal will be dealt with in a separate communication.
- d) Mr. Juan Sebastian Ruiz will update the network on the possibility to help validate software MINERVA.

- e) Dr. Maria Angeles de Miquel will give us an updated plan for participation in Training School #2.
- f) Axel Kohlmetz will keep IRENE posted on the development of Rehab program.
- g) Prof. Hendrik Knoche will approach IRENE members regarding RES-Q interviews.

At the very end, Ms. Svobodova announced that the meetings of our network will be more frequent and task-specific. Prof. Bornstein thanked the team in Brno for the organisation and expressed his hope that the year 2021 will be for us very productive.

SIMKOVIC/ 15th of March 2021