RES-Q Update April 2018

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Current Data Collection Period

The official start of data collection was <u>March 1st, 2018,</u> **and it concluded on** <u>March 31st, 2018</u> (these dates represent patient admission dates).

For inclusion in preliminary results prior to ESOC 2018, all data must be entered in RES-Q by <u>April 20th, 2018</u>.

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Important Data Collection Guidelines

1. There are currently two RES-Q forms available, RESQv1.2 and RES-Qv2.0-dev, **and only one of these forms needs to be filled out for each patient**. RESQv1.2 is the original questionnaire, and can still be used for this data collection period. RES-Qv2.0-dev is the updated form based on feedback from 2017, however it contains the same metrics as RESQv1.2, it only adds 2 additional diagnoses (TIA and Venous Thrombosis) and some additional options for more complex patient pathways.

2. **For hospitals only participating in RES-Q which do not collect data continuously,** the current data collection period concluded on March 31st, 2018. Data can still be entered until April 15th for inclusion in preliminary results for ESOC 2018.

3. The minimum required data collection is 30 consecutive patients.

4. **For hospitals which did not have the minimum 30 patients required in the March collection period, data can be entered retrospectively from February 2018 as well.** Data can always be entered retrospectively; the only important consideration is that data entered should be for consecutive patients in order to obtain an accurate representation of ongoing stroke treatment processes.

5. **For hospitals participating in the ESO Angels Awards program,** data for the first quarter of 2018 (January – March) will be used. For sites which will not have 30 consecutive patients within the given time period, patients admitted prior to the data collection period may be entered such that they still represent 30 consecutive patients (i.e. that collection period could be e.g. February 15 till March 31 to obtain sample of 30 patients).

6. National coordinators will be provided with a summary of data entry for all hospitals in their country at the mid-point (~March 19th); after the end of preliminary data collection (~April 15th); and after data is finalized (~June 1st).

7. National summary reports (summary statistics broken down per hospital), including ESO Angels Awards status, will be sent to National Coordinators after the conclusion of data collection.

RES-Q Update

RES-Q launched in November of 2016 with 20 participating countries. In the previous update in February of this year, there were 350 participating hospitals, which had contributed data for 20,000 patients. The current data collection period has been a tremendous success, and we are happy to report that **there are now 440 hospitals participating in RES-Q, from 42 countries, with more than 30,000 patients contributed.** This still does not represent the conclusion of the current data collection period, so there is still plenty of time to finalize data entry prior to the April 15th deadline for preliminary ESOC 2018 data.

SEASK Meeting

RES-Q was officially launched in South-East Asia in early March of 2018 at the annual SEASK regional meeting. Representatives from Indonesia, Malaysia, the Philippines, Singapore, South Korea, Thailand, and Vietnam met to discuss initiatives for improving stroke care quality in the region. RES-Q was presented as a tool for measuring key metrics, and providing comparative results with other hospitals nationally, and internationally. **Currently there are 17 hospitals from the SEASK region enrolled in RES-Q, and several have already begun using the registry for quality of care monitoring.** We would like to welcome all of the SEASK participating members to RES-Q, and we look forward to ongoing collaboration in the future.

Social Media Updates

To help improve communication, and provide more timely updates, RES-Q has recently joined social media. Currently, you can follow the RES-Q project on Facebook: https://www.facebook.com/RegistryofStroke and Twitter: https://twitter.com/RegistryStroke, with LinkedIn and others to be added soon. We usually provide new information and updates several times a week, so it is a great way to stay informed, or to contact us with questions and feedback. If you have news or updates from your own organization and would like to connect and share with RES-Q, please let us know, and we would be happy to collaborate with you.

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ESO Angels Awards

As we announced in the last update, RES-Q is an official registry for the **ESO Angels Awards** as part of the ESO Quality Improvement Programme. If your hospital is interested in being considered for an ESO Angels Award, please make sure all of your data is entered into RES-Q prior to April 15th, 2018. We will begin processing the data after this date to determine hospital eligibility for the awards. From hospitals that have been using RES-Q for ongoing data collection in 2017, and the first quarter of 2018, there are already more than 20 hospitals which have qualified for awards. We look forward to seeing many more hospitals recognized for their excellence in stroke care.

The ESO Angels Awards are conferred quarterly throughout the year, and many RES-Q sites are now collecting data year-round to participate in this program. **If your country is not currently participating in the ESO Angels Awards program, but would like to, please let us know.** All that is required is the agreement of your country to participate, and then the required summary data can be automatically submitted from RES-Q to the ESO Angels Awards committee for quarterly review.

⚠️ Continuous data collection from sites can always be done, and requires no additional notification to RES-Q or participation in the ESO Angels Awards.

New RES-Q Form

For the 2018 data collection period, a new version of the RES-Q questionnaire was made available. This updated questionnaire adds two new stroke types (TIA and Venous Thrombosis) as well as more options for patient pathways. The updated questionnaire still contains all of the data from the initial version however, so hospitals can continue using the previous version for this data collection period if they choose.

It is important to note though, **only ONE version of the questionnaire needs to be completed**. Hospitals can choose to fill in either RESQv1.2 or RES-Qv2.0-dev, but they do not need to fill in both. RESQv1.2 is expected to remain available until mid-2018, when all updates to the new form will be finalized, at which point RES-Qv2 will become the official form.

ℹ️ The updated form is currently available in English, Czech, Romanian, and Ukrainian.

If you would like to have the form translated for your country, please let us know and we will send you a structured document you can translate. Once we have the translation from you, we can implement it in the online form.

GDPR

On May 25th, 2018 the new General Data Protection Regulations (GDPR) for the European Union will come into effect. Prior to this date, we will provide a more complete document addressing the relevant sections of GDPR and how they impact RES-Q.

RES-Q was developed with the GDPR framework in mind, and already applies many of the principles that will be required under the new legislation. Sensitive data is maintained securely, and data minimization has been a central component of the registry design, so only the most necessary data is stored, and additional identifiable data is avoided.

We expect minimal impact on the registry when GDPR becomes effective due to this design, but we will make the full documentation available on the website prior to the May 25th deadline.

We will also be presenting the practical application of GDPR to RES-Q during the e-poster discussion session at ESOC on May 17th at 18:10, so you are also invited to come discuss with us then:
https://cmoffice.kenes.com/cmsearchableprogrammeV15/conferencemanager/programme/personid/anonymous/ESOC18/normal/b833d15f547f3cf698a5e922754684fa334885ed#!abstractdetails/0000181841

You can find the entire text of the GDPR in the Official Journal of the European Union:
https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=celex%3A32016R0679
The European Comission's site on EU data protection rules:
https://ec.europa.eu/commission/priorities/justice-and-fundamental-rights/data-protection/2018-reform-eu-data-protection-rules_en