STROKE
2020

A Participation Guide for national societies, regions and hospitals.

October 2018

Welcome to the Stroke 2020 Participation Guide.

This guide is intended to be used by anyone considering participation in Stroke 2020. It will provide you with all the information you need to participate. We look forward to welcoming you joining Stroke 2020 and the continued journey in improving stroke care quality.

All data provided to Stroke 2020, whether through data entered directly in RES-Q, a national registry, or the Angels Stopwatch app, will be processed by RES-Q. Anybody considering participation in Stroke 2020 should ensure they have the relevant permissions for data sharing. You will find full details of the RES-Q data sharing policies in the FAQ section at the end of this document.

Stroke 2020 Participation Declaration

There are three levels of participation for Stroke 20 20 20.

1. National Participation
2. Regional Participation
3. Hospital Participation

The table below provides a summary of the participation levels:

Data for March 2019 & March 2020	National	Regional	Hospital
Total number of ischemic strokes national / regional	✓	✓	
Total number of patients receiving IV tPA	✓	✓	✓
Median Door to Needle Time	✓	✓	✓

1. National Participation

National participation in Stroke 2020 is intended to provide **a comprehensive picture of how a country performs** against the campaign benchmark: 20% of stroke patients should receive IVtPA and it should be administered within 20 minutes of admission to hospital, at population level (including ischemic stroke patients not treated in a recognised stroke centre).

To participate in Stroke 2020 a National Society should:

i. Agree on how data for Stroke 2020 will be collected. Options can include:
   - RES-Q, an ESO Quality Registry: www.qualityregistry.eu
   - National Stroke Registry

- Angels Stopwatch App for Android or Apple

ii. Agree on a data source for collating total number of strokes to be used for calculating thrombolysis rate.

iii. Head/s of the National society should write on behalf of the society, declaring their intention to participate in Stroke 2020, including their methodology for data collection, to be included on the Stroke 2020 website, www.qualityregistry.eu/2020

Inclusion on the Stroke 2020 website would mean that the declaration letter and methodology would be publically available so that they might inspire others to join.

If you would like a national society logo included with your declaration, please send it with your letter and we will be happy to include it.

iv. Provide one month of data to Stroke 2020 for March 2019 and March 2020, using the methodology described in the National Society Declaration letter.

v. Commit to use collected data to highlight where improvements in acute stroke care can be made and engage government, and all critical stakeholders to make those improvement.

2. Regional Participation

If country-level participation in Stroke 2020 is not feasible, we would welcome contributions from regional health bodies.

As with national participation, regional participation in Stroke 2020 is intended to provide **a comprehensive picture of how a recognised region within the country performs** against the benchmark of 20% of stroke patients being treated with IV tPA and the bolus being administered within 20 minutes of admission, at population level (including ischemic stroke patients not treated in a recognised stroke centre).

Those wishing to participate on a regional basis should:

i. Agree on how data for Stroke 2020 will be collected. Options can include:
- RES-Q, an ESO Quality Registry: www.qualityregistry.eu
- Regional data taken from a National Stroke Registry
- Angels Stopwatch App for Android or Apple

ii. Agree on a data source for collating total number of strokes to be used for calculating thrombolysis rate.

iii. The stroke lead for the region should write, declaring their intention to participate in Stroke 2020, including their methodology for data collection, to be included on the Stroke 2020 website, www.qualityregistry.eu/2020

Inclusion on the Stroke 2020 website would mean that the declaration letter and methodology would be publically available so that they might inspire others to join.

If you would like a regional logo included with your declaration, please send it with your letter and we will be happy to include it.

iv. Provide one month of data to Stroke 2020 for March 2019 and March 2020.

v. Commit to use collected data to highlight where improvements in acute stroke care can be made and engage local and regional government, and all critical stakeholders to make those improvements.

3. Hospital Participation

We also welcome participation from those hospitals that would like to benchmark their performance against hospitals from across Europe.

To participate on a site level, a hospital should:

i. Agree on how data for Stroke 2020 will be collected.
   - RES-Q, an ESO Quality Registry: www.qualityregistry.eu
   - Individual hospital data taken from a National Stroke Registry
   - Angels Stopwatch App for Android or Apple

ii. Agree data source for collating total number of strokes to be used for calculating thrombolysis rate.

iii. The stroke lead for the hopital should write, declaring their intention to participate in Stroke 2020, including their methodology for data collection, to be included on the Stroke 2020 website. www.qualityregistry.eu/2020

Frequently asked questions

1. How can I collect data for participation in Stroke 2020?

There are three ways to provide data for participation in Stroke 2020.

i.   Provide data taken from a recognised National Registry.
ii. Register with RES-Q and the data for Stroke 2020 will automatically collate the data for Stroke 2020.
iii. Use the Angels Stopwatch App. This data can be sent automatically by registering with RES-Q.

2. How do I register with RES-Q?

RES-Q has a simple 1 page form that can be found by clicking <u>here</u>. If a country or region wishes to participate in Stroke 2020 and is not registered with RES-Q, each hospital will need to register separately. If you have any questions on how to register, please contact admin@qualityregistry.eu Alternatively RES-Q is happy to provide a spreadsheet that the society can complete and we will forward registration details to each centre.

3. What information does my National Registry need to send and by when?

When a National Society declares to participate in Stroke 2020 the following data is required for March 2019 and March 2020.

i.   Total number of ischemic strokes nationally for March 2019 & 2020.
ii. Total number of patients receiving IV tPA for March 2019 & 2020.
iii. Median door to needle time.

4. Why is the data collection period for only one month each year?

Stroke 2020 deems that 1 month of data provides sufficient information to construct an accurate view of how acute stroke is treated nationally, regionally or within an individual hospital.

Providing data for the same time period for two consecutive years allows countries to demonstrate progress towards the goal of treating 20% of ischemic stroke patients with IV tPA and highlights the gaps that are still present.

5. How will Stroke 2020 use the data?

The primary purpose of Stroke 2020 is to encourage paticipants to collect the data that ascertains performance in two key metrics of acute stroke treatment. This data will be used to engage relevant stakeholders to improve performance where appropriate. However, if the data collected is sufficient, Stroke 2020 would welcome the opportunity to collaborate with all participants to publish it.

6. How will RES-Q store my data?

The complete RES-Q data storage policy can be found on the RES-Q website, <u>RES-Q Data Security Policy.</u> RES-Q complies with all legislation pertaining to the receipt,storage and dissemination of data.

7. Will my declaration be published, and why?

Yes.

The more countries, regions and hospitals that participate in Stroke 2020 the more effective the campaign will be. All declarations will be published on the Stroke 2020 website, hosted at <u>www.qualityregistry.eu/2020</u>. Published declarations will be used to offer guidance and inspiration to other societies to join the campaign and share their plans.

8. How will my declaration be published?

As we wish all declarations to be public, Stroke 2020 will publish declaration letters as they are received. The Stroke 2020 website has a sample letter that all potential participants are welcome to adapt for their own use.

9. Will my country/region/hospital data be publicly available?

All data sent to Stroke 2020 will remain the property of the organisation that sent it. Stroke 2020 will only publish aggregate results data based on the participation level you have selected. Source data will not be published without explicit permission of the owners of the data.

10. Why does Stroke 2020 want the overrall number of ischemic stoke patients for a country/region?

Some countries have very well developed plans for the treatment of acute stroke, with co-ordination between ambulance services and a network of approved stroke centres. However, even in these countries some patients are not treated in a stroke centre. Including all ischemic strokes, not just those that were treated in a stroke centre, gives a more accurate picture of what percentage of patients receive IV tPA at a population level.

11. Will participation in Stroke 2020 require ethical approval?

As patient data will be sent (albeit in an anonymysed form) ethics approval may be needed before participation in Stroke 2020. Please ensure you have all neccesary ethics approvals before participating in Stroke 2020.

12. Do I need to be registered with RES-Q to use the Angels Stopwatch App for Stroke 2020?

It is possible to use the Angels Stopwatch app without registering with RES-Q, however registering with RES-Q will allow clinician to automatically upload the data and mean that data collected by different clinicians in the same hospital will automatically be allocated to that hospital. Alternatively Angels Stopwatch App users can forward their data manually.

13. What assistance will Stroke 2020 provide?

Stroke 2020 will encourage all participants to share how they are working towards their target for 2020. We will share success stories, methodologies and results. Every participant, whether a country, region or hospital will be publically acknowledged as working to improve the quality of stroke care. ESO EAST also provides support for those wanting to improve stroke care and would welcome any participating countries who are not currently part of the project to join and work towards 'Enhancing and Accelerating Stroke Treatment'.

Partner Organisations

TBD