Stroke Action Plan for Europe national coordinator meeting Lisbon, 30-31 January 2024 - Report

We brought together 60 Stroke Action Plan for Europe (SAP-E) national coordinators (NCs) and 35 European countries:

- To meet and engage in person with national coordinators
- For them to feel engaged in the SAP-E work
- To energise, inspire and build the team spirit
- To share information on success and challenges and practical action with a specific focus on the stroke services tracker (SST), advocacy and regional activities

Opening message, Hanne Christensen, Chair SAP-E
Hanne welcomed everyone and discussed the importance of networking and learning from each other.

She shared with the news that Melinda Roaldsen, our SAP-E COO, is recovering from her recent stroke – we wish her a speedy recovery. Aleš Tomek will temporarily step in as her replacement. Hanne also shared the news that Peter Vögele had passed away. He was an inspiring colleague and we send his family our condolences.

She also thanked the NCs for all their work - 13 countries have signed the Declaration and everyone is working hard on submitting the SST data. In addition, the SAP-E 2019-2030 is currently being updated. It will be published in the European Journal of Stroke and will be followed by a webinar session to update the NCs on this in the summer.

In our first session we discussed data and the SAP-E services stroke tracker

Working with quality data – examples from the Danish Stroke Register, Dorte Damgaard/Denmark
The aim of the register is to improve the quality of treatment for patients with acute stroke and TIA by measuring implementation of national stroke guidelines. She told us that:

- Moving from manual data entry to automated requisition of data from electronic records has improved efficiency and accuracy of the data used
- Presenting data on maps for example is a better way of showing data and areas of improvement over years
- The data goes to all the hospitals and is discussed with key policy makers in the hospitals
- Example was first evaluation by physiotherapist and occupational therapist to estimate need for rehabilitation <48 hours. Until recently, there were three options for this item: done – not done – not relevant. Large differences have been observed in 'not relevant, wherefore this option was removed and at the same time the % needed to meet this KPI was reduced.

Services Stroke Tracker (SST) – 'why, how to complete, how to use it', Hanne Christensen, Chair SAP-E
She outlined:

- The data is a strong tool to change practice
- The SAP-E and Essentials of stroke care document describes the state-of-the-art care people should receive
- However, there are variations across Europe
- The SST underlines the basic need for stroke data – it allows for oversight, comparison and countries over time, it shows what is going on and where improvement needs to be made
- We need the best data that the SAP-E NCs can provide – this could be either nationwide, audited and cross-referenced data or expert estimate
- Tips – don't use the 'start over button' – and use Google Chrome to avoid browser problems!!!
- Data will be presented at ESOC in May when we are holding the next SAP-E NC meeting

Good examples of how to use the data were presented by three from SAP-E NCs

Sarah Belson/UK
- o The SAP-E work in the UK is a collaboration between the SSO and professional body, involving the four separate nations with four separate data sets (SNAPP and the Scottish Stroke Care Audit)
- o She outlined how the Stroke Association/an SSO has used the data for advocacy purposes
- o Using KPI7b – rate of ischemic stroke treated with mech thrombectomy – the Stroke Association launched: [Saving brain campaign](#)
  - ▪ Their message was that MT saves brains, money and lives, but access varies with 80% missed out on treatment in 2021
  - ▪ Their campaign involved parliament questions, the media, a petition to parliament and a one year update publication on progress
  - ▪ Comparing with other countries has been historically difficult for the Stroke Association – with questions around quality/robustness of data and who to compare to – but parliamentarians are asking for it. They are now using the SST maps with comparisons with specific countries and commentary, including international policy recommendations from WHO

Aleš Tomek/Czech Republic
- o He presented the Czech national strategy for moving forward improvements in stroke care using SST data
- o Negotiations with politicians have involved telling them where things are going well (acute care - e.g. IVT rate) before discussing what could be improved
- o Using the SST data, they have identified the following priorities:
  - ▪ Increasing the number of people treated in dedicated stroke unit – they have plans to improve the stroke unit network for example setting up 2-5 new units, with the help of the ministries
  - ▪ Reducing onset to needle time by working with the ambulance service for example
  - ▪ Reviving the coalition of SSOs and scientific societies to address their gap in KPI2 involvement of SSOs
  - ▪ Future plans include: working on primary prevention, ICH mortality, acute rehabilitation and LAS

Zuzana Gdovinova/Slovakia
- o WHO launched a health mission in their country – they were able to change the stroke definition to brain disease from heart disease
- o They are good at MT in their country – this is due to the doctors not the government – as the EU funds have not been spent on this area
- o Their focus is on improving rehabilitation and have shared data on rehabilitation to ministry. They know rehabilitation is not as planned as it should be – 35% / 4,000 are suitable but the registry data showed 4% are receiving it – and no system for rehabilitation at home. These very clear arguments have been shared with for ministers
- o They have used national registry data, RESQ data and SAP-E data

This was followed by workshops on 'Using the Services Stroke Tracker (SST) in your advocacy work in 2024'

The NCs worked in their regional groups, facilitated by the regional spokespeople (Aleksandars Vilionskis, Hrvoje Budincevic, Ales Tomek and Gustavo Santo). In advance, everyone had reviewed their own country's SST data from the SAP-E website. At the workshop each NC presented their biggest challenge as outlined in their SST data. The group then decided to pick one country and one problem they wanted to focus on. They discussed the issue, challenges, opportunities, and solutions. Each group was asked to develop an advocacy strategy, plan and supporting communications plan for the issue in that country.

(Appendix 1 for two examples of an advocacy plan)

Our afternoon session focussed on 'Keeping stroke high on the health policy decision making agenda'

Our first two presenters shared their experience of working with the media to raise awareness of stroke.

Patricia Rebelo, Portugal
- Health journalist, works with the Portuguese stroke society, raising awareness of stroke
- Media:
  - Use media to deliver message to different audiences
  - Select the target and then the message
  - Repeat the message throughout the year to different audiences
- Use awareness days
- Use channels - online, press, tv and radio – this is good and can reach a lot of people, but it depends on meeting their agenda and getting the airtime
- Social media can be used to suit the agenda of the society/SSO – Facebook, Instagram, LinkedIn, X – post every day and different audiences can be targeted with different information

Andras Folyovich, Hungary
- In order to improve stroke care it is important to communicate the needs of neurology and stroke care
- The media is the tool to reach important targets
- As well as being a neurologist, he has a new role on Duna TV – once a month he hosts a television show – where he can get across important messages about stroke, repetition is key
- Key projects they are raising awareness of include: Fast Heros in kindergartens and secondary schools, National screening plan buses, their dysphagia project and they have linked to a National Ambulances Service app

Our next speakers gave practical examples of keeping stroke high on government agendas

Stroke, MEPs and the European Parliament, Arlene Wilkie, Stroke Alliance for Europe
- Opportunity – European Alliance for Cardiovascular Health, specifically an event at the EU parliament in Strasbourg
- Call to action – cardiovascular health plan
- Target – MEPs interested in health who are standing for re-election
- Pre-event activity – SAFE members and ESO reps arranged to meet MEPs at the EU parliament at the EACH exhibition event; briefing/data documents on stroke created for the MEPs; attendees fully briefed
- Activity on the day – SAFE members and ESO discussed data with the MEPs, shared experiences, discussed solutions, signed a pledge wall, had photographs taken and took part in an interview with the SAFE/ESO reps
- Success on the day – SAFE/ESO met with 35 MEPs
- Post event work – MEPs encouraged to promote their support for the CVH plan on social media to their constituents; several SAFE/ESO attendees have held follow meetings, and one MEP has asked a parliamentary question
- Next steps – SAFE members and SAP-E NCs will be asked to approach MEPs standing for election at the elections in June to ask them to include health and stroke in their election manifestos, we will contact them after the summer and invite them to an event where we launch the new SAP-E.

Influencing politicians the Italian way, Francesca Romana Pezzella
Francesca outlined some tops tips for the SAP-E NC when developing their plans:
- How can NCs work out who are the key departments and people to work with – spend time doing desk research. NCs need to review the departments, the legislation, the policies that the government is focusing/working in – it is likely that stroke will fall in many areas
- Who should SAP-E NCs should work with – use the information above and carry out a stakeholder analysis – who are the key departments that can help with the issue/problem you have identified
  - This is a really important step. It is crucial that NCs work with the people who are actually responsible for the issue that you are raising, that they are the ones who can take action and make the change you are looking for. For example, Fast Heros is the responsibility of the national education department in Italy not the health department. And they are considering that perhaps the SAP-E could be signed at a regional level in Italy as these officials are the ones elected by the public in their federal political system
- When should SAP-E NCs raise awareness – always, but use stroke days

Regional examples

Yuriy Flomin/Ukraine
We were delighted to hear from Yury who dialled in on Zoom from the Ukraine:
- He discussed the global burden of disease data for Ukraine
- He presented a piece of research that had been done, looking at the SAP-E KPIs and comparing the Ukraine's performance using a traffic light system ie red = bad, amber =ok, green = good
- This work will be published and will be used to develop the priority stroke work in the Ukraine
- SAP-E NCs are encouraged to use this traffic light system as a means of working with policy makers and setting priorities priorities for stroke for the next year

Wilfried Lang/Austria
- Wilfred explained that SAP-E has enabled conversations with policy makers in his country.
- Austria has a federal system like Italy - nine regional governments, and there is a ministry of health, all decisions have to be made with all partners
- Their work has resulted in an agreement between regional governments and ministers that the SAP-E will be integrated into the new quality standards of stroke care in Austria, for example, including ICD 10, brain imaging, recanalisation, mortality, time intervals of care, and post stoke care including the Stoke Card.

Group work
Here, the NCs were split in non-regional groups facilitated by the Regional Spokespeople and the groups were asked to discuss their individual strategies for keeping stroke high on the decision making agenda including:
- Strengths/opportunities of our NCs and the work they are coordinating in their countries
- What do you want to achieve
- Who are you talking to/working with
- What are the big/common questions are they asking
- What data/evidence etc. are you using to answer the questions

On the final day, the focus was for colleagues to share advances made in improving stroke care and support across the whole stroke pathway

We started with a quick fire round where each NC presented advances in stroke care and support (acute/secondary prevention/rehabilitation/life after stroke) in 2023.

Here is the link to individual countries' advances.

Before breaking into final breakouts facilitated again by the Regional Spokespeople, where the NCs discussed their activities and priorities for 2024.

Appendix 1 - Two examples of an advocacy plan

Belgium
The problem:
Belgium does not know its stroke data and so therefore can not plan for effective treatment and support of those affected by stroke leading to inequality of care throughout the country

- 11 million people
- 26 centres performing thrombectomy (there are no formal accreditations, in 2023-2024 4 stroke centres are recognised in Wallonia, Flanders and Brussels are lagging behind).
- No national registry
- No national stroke plan
- No stroke code
- No stroke unit audits
- No patient experience data

Opportunities:
- There are stroke groups that are already exist – they could be better connected
- Work with the Belgian Alliance for Cardiovascular Health
- Learn from other conditions that are a government focus

What would change look like
A national stroke registry in Belgium

Activities
1. Identify regional stroke leaders
2. Prepare evidence of quality of care
   1. using the Essentials of stroke care or the 12 KPIs – develop a 'traffic light system' of green/amber, red to show where things are good and not so good
   2. review the patient journey for stroke care (though to life after stroke), review services available and identify gaps in care provision
   3. Review Belgium epidemiology/data/economics and be clear on the current stroke numbers in Belgium
3. Host a stroke leaders meeting to determine the key priorities for stroke care in Belgium and why a national stroke registry is key to demonstrate improvement
4. Identify key government policy levers based on the key priorities identified including:
   1. Which departments are responsible
   2. Who are the key people responsible
   3. What legislation/guidance/strategies etc etc that already exist that are relevant to the priorities
   4. Who is responsible for the funding
5. Develop an structure of what a national registry needs to capture
   - This data could initially be collected by stroke units and rehab centres as a predecessor to an official stroke register

6. Develop an outline of good stroke care in Belgium (a white paper?) with the stroke leaders and the key government people – and launch with pledges and signatures on European or World Stroke Day

Risks and mitigations
- No stroke leader buy in – seek out and actively/regularly engage with a small group of key individuals from across the stroke pathway including AHPs and those with lived experience
- No political buy in – align with current policies and thinking to make it relevant

Montenegro
Montenegro: stroke and health system at a glance
- Population: 620,029
- Health System: tax-funded health insurance system.
- Mortality registry: yes
- Stroke registry: no
- According to the latest WHO data published in 2020 Stroke Deaths in Montenegro reached 2,208 or 33.49% of total deaths.
- The age adjusted Death Rate is 184.75 per 100,000 of population, ranks Montenegro #8 in the world.
- In 2025 50 neurologists in total
- 7 Hospital+ Clinical center admitting stroke patients
- Montenegro: Neurologists per 100,000 people
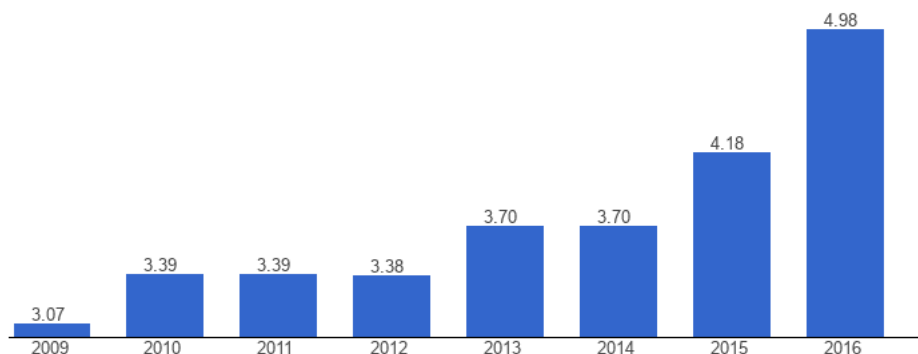
What is the biggest issue/challenge/problem in Montenegro
- no stroke system of care
- no stroke registry
- lack of neurologists
- a lot of NA in the SST

What are the opportunities/solutions: use data for decision- making purposes.
- Infrastructure and protocols: 1 stroke unit in the country (6), Stroke nurse, Rehab, Speech therapist, Thrombolysis available, Thrombectomy available (2 specialist), no stroke code, Neuro rehabilitation, DRG

- Stroke Clinical   Pathway: National Stroke Programme, IT, Operational monitoring and evaluation system: data collection is fragmented, statistics are often not publicly available; provider payment mechanisms are not linked to performance and quality of care
- Project implementing SAP-E and collect RES Q data
  - Timeline: 1 year project (2 months –Israel model- March November)
  - Tool: RES Q /IT
  - Measures: number of patients in the Registry cross referenced with DRG /definition of a set of stroke indicators (KPIs of SAP-E)
  - Risks and mitigations: audit of recorded data after each registry month (have a registry team and an audit team)
  - use data for decision- making purposes

Who are you going to work with
- MoH, Montenegro Stroke Society, Association of Neurologists, WHO CO, Ambulance Service, ESO and ESO EAST, Angels, SAP-E
- Timeline: 1st meeting to present the project (25th Feb) to gain general consensus
- Measures: participations in meetings/number of hospitals register in RES Q (X/7)
- Risks and mitigations: management of expectations of neurologists- awards – incentives free education- participation in Angels activity

What activities are you going to carry out
- RES Q data collection March and November 2024
- SAP-E declaration signature (MoH is opening Neurology Conference)
- Medical education focusing on all aspects of stroke care (ESO material-Angels initiative)
- Measures: declaration sign yes or no /Res Q
- Number of educational events and type
- Number of professional exposed
- Pre and post educational knowledge questionnaire
- If no consensus obtained – postpone the actions

What would success look like
- Stroke report presented and disseminated
- Declaration signed
- Commitment to National Strategy
- Essential of Stroke Care translated in Montenegrin
- Stroke awareness campaign
- Educational activities on stroke
- Stroke course for health allied professionals

Communication plan
What are your key messages
  - Mortality (premature) is high and people is dying for a preventable and treatable condition

- o We can do more and we have the resources to do it quickly
- o Access European Resources / reach European standard of care
- o Who are your audiences
- o Stakeholders + Population

What communication channels will you use
- o Social Media (Instagram)
- o Participation in TV /newspapers
- o Stroke Champion: Musician Sergej Cetkovic