SAP-E NATIONAL COORDINATORS MEETING

4 to 5 MAY 2025 – EVENT REPORT

Day 1: Monday 4 May

Welcome and General overview - Status of SAPE in Europe, goals and activities
Francesca Romana Pezzella

Francesca Romana Pezzella (FRP) opened the event with a broad overview of SAPE's progress and priorities across Europe. She highlighted the updated review of SAP-E, including revised KPIs, targets and supporting evidence, alongside encouraging progress on national stroke planning, with around 20 countries now developing or implementing stroke plans and further publications expected. She also reflected on the SAP-E's development over time, from its early launches and joint working with SAFE and ESO to its relaunch in Brussels, underlining SAP-E's role as a shared European framework for driving stroke care improvement.

A central theme was the importance of the Stroke Service Tracker (SST), SAP-E's annual collection of data against agreed KPIs, which allows countries to monitor performance, compare results and identify where stroke care needs to improve. Current gaps remain significant, particularly in access to stroke units, rehabilitation, early supported discharge, secondary prevention and life after stroke services, with better quality data still needed to support decision-making.

FRP also pointed to important policy opportunities, including the launch of the EU Cardiovascular Health Plan and the anticipated WHO stroke resolution, both of which could strengthen national action if governments engage actively. Looking ahead, she noted new links with ESO Fellows and ESO-East and shared the example of the Czech Republic's ambulance tracking tool https://timeskill.com/mzd/zzs/spady/praha_a_sck, which has helped reorganise the stroke network and demonstrates how practical innovation can improve the patient pathway.

Three take home messages:

1. SAP-E is the European implementation platform for stroke care improvement
2. 2030 success depends on national plans, data, accountability and targeted support.
3. Patients, survivors, carers and equity must remain at the centre

Country presentations: Opportunities and challenges

The slide deck of the country presentations is available here.

Albania: expansion of stroke unit care and introduction of thrombolysis; problems with rehabilitation and LAS after leaving hospital, most important is the role for patients.

Armenia: launch of the national stroke database measuring acute and sub-acute in hospital; new stroke unit in south Armenia; new insurance system which may help improve secondary prevention; expanding rehab including multidisciplinary; no LAS advances.

Austria: new quality standard of stroke and new bench-mark system aligned with the SAP-E; more stroke beds are planned; LAS post stroke app is in development looking at secondary prevention and outcomes.

Belarus: MoH and council of ministers increased attention; acute care is improving; LAS minister of social protection has introduced pension for the disabled, benefits for the cost of medicines, technical means of rehabilitation for free or at a reduced price.

Belgium: first national stroke care meeting with a focus on stroke care plan and stroke registry and first national stroke audit; improvements in stroke care; no updates on rehab, secondary prevention or LAS.

Bosnia and Herzegovina: EMS education for acute care; increased thrombolysis.

Bulgaria: national stroke plan has been updated and there is a new TIA clinical pathway.

Catalonia: new platform for national stroke registry; 2 new primary plus centers (stroke unit and endovascular treatment); secondary prevention - developed several projects about rehabilitation audit.

Croatia: national stroke registry; improving stroke care; secondary prevention medicines and procedures in place.

Czech Republic: stroke data is available online; 8 new stroke centres and highest rate of recanalisation; reimbursement of secondary prevention; new triage for rehabilitation; unit coordinators who will arrange pathway after hospital for each patient including social services.

Cyprus: social and SSO coordinating the national stroke conference; established new national stroke center; developed a patient journey pathway for secondary prevention; promoting MDT rehab; LAS – new young stroke survivors research project.

Denmark: SSO and neuro society worked together to update the stroke plan; new rehab register approved by the government; national health care system restructure should improve SSP.

England: rolling out AI tools across 107 stroke centres, recues treatment times by approx. 1 hour; faster imaging and expanding; new 10-year plan will improve secondary stroke prevention and new women's health strategy launched. Access to rehabilitation and early supported discharge increased; neuroniline and bridges for LAS.

Estonia; national stroke care pathway development with the insurance fund – is improving acute care, secondary prevention, rehabilitation and LAS.

Finland: continuing with Perfect Stroke Registry; launching national stroke awareness campaign; improved secondary stroke prevention including BP and statin access.

France: direct access to national reimbursement database; nationwide working group set up to address acute care.

Georgia: ongoing certification of primary and secondary stroke centres, involving the MoH; improving acute care and access to secondary stroke medications and access to rehabilitation centres.

Germany: national stroke research network funded by the German Health Ministry; acute care and secondary stroke prevention well organised; working on better collaborations between GPs and neurologists to improve SSP; rehab – spasticity brochure published.

Hungary: stroke league remains; tracking quality control; new dysphagia project – focusing on diet; secondary prevention - working closely with GPs and new brochures; new brochures for stroke survivors and relatives.

Iceland: working towards signing the SAPE declaration; new MSc in neuro nursing; new geriatric stroke unit; up to 2-year rehabilitation for stroke patients who ae cognitively impaired; first draft of rehab care bundles approved.

Isreal: new MoH directive for acute care is law and must be implemented; improving acute care; implementing interdisciplinary practice with cardiology and internal medicine to improve secondary

stroke prevention; new funding from government to improve stroke rehabilitation; LAS - online lectures to address post stroke.

Italy: first draft of national stroke plan: acute care improving; secondary stroke prevention – working on position/consensus paper; rehab – national consensus to calculate current coverage; LAS – podcasts for patients and caregivers.

Kyrgysztan: SAPE declaration signed; starting thrombolysis; access to secondary stroke prevention medication; early rehab – only available in private; late rehab covered by government; LAS – follow up at 6 months.

Latvia: Riga recognized as first city recognized as Angels region; thrombolysis improving, secondary stroke prevention all medications are available and recognized.

Lithuania: Stroke guidelines updated; acute care improving; more prescribing and reimbursement of medications; MoH order – on long term outpatient care for stroke patients.

Moldova: function stroke network = improved access to stroke care and public awareness of stroke; increased thrombolysis; secondary stroke prevention – access to medications improved through reimbursement of nation health insurance company; translated secondary stroke prevention guidelines for patients; rehab – project to modernise and improve rehab services; LAS implemented 3 month follow up by phone and developing digital platform for stroke survivors and caregivers.

Montenegro: first annual conference including MoH and WHO – hopefully more to report next year; in hospital rehab has increased.

Netherlands: 2 round tables for ground work for national stroke plan which they hope will be launched this year; stroke care well organised by access varies across regional, AI image guided treatment system; secondary stroke prevention – focus on gender responsive care and prevention to reduce inequalities; rehabilitation - push to include daily life in follow-up visits; LAS – co-designed PREMs with stroke survivors to strengthening service deliver across entire chain of care; problems – 3 months follow up, lack of community rehab, no stroke unit certification.

Norway: national IVT survey shows geo variation; national stroke network; trying to get AI support tools for imaging into national plans; annual audit of stroke units.

Northern Ireland: regional approach to recording data and meeting standards in SSNAP; aligning with national guidelines; rolling out AI in stroke units for imaging; SSP – implementing TIA pathway – focus on standardising monitoring; rehab pilots; LAS – update of ‘my stroke journey’ for patients.

Poland: new software for all stroke unites by MoH; improving acute care; secondary stroke prevention – improving access to medications and reimbursements.

Portugal: expansion of stroke unit networks and thrombectomy centers.

Scotland: continued roll out of thrombectomy but still not fully available across the country; updated stroke standards and definitions; aligning data with SSNAP; secondary stroke prevention – government working on CVD prescribing guidelines; rehab – pilot rehab audit; 6-month review now routine.

Serbia: new stroke guideline completed; functional network between stroke centre and stroke ready hospital; raising awareness of secondary stroke prevention with GPs; increasing speech language in hospital; peer to peer support with stroke survivors.

Slovakia: Angels awards; improved access to acute care medications; access to secondary stroke prevention medications.

Slovenia: defining stroke pathways and aligning with European practice; telemedicine network is working but not enough stroke units; secondary stroke prevention – improved data collection and implementation of guidelines; rehab provided to inpatients at stroke unit but availability to MDT rehabilitation out of hospital is limited.

Spain: stroke unit survey to evaluate the impact of the stroke plan; secondary stroke prevention /rehabilitation/LAS – collaboration with MOH on webinars.

Swedish: increasing reperfusion and thrombolysis; stable use of stroke units, prescription rate of secondary stroke prevention s and satisfaction with acute rehabilitation; late rehabilitation is a challenge as is follow up.

Romania: EU research project – to train stroke specialists in acute care = incl new national guidelines, registry updated; new CardioV and CerebroV disease plan launched; improved stroke care; new acute care rehabilitation programme.

Ukraine: quality monitoring and improvement; improvements in acute and rehab access; secondary stroke prevention – government includes DOAC in funded program; LAS publication with MoH.

Wales: developed the quality statement and service standards; thrombectomy centre opened; secondary stroke prevention – increased screening in primary care to prevent strokes; LAS – quality statement for LAS – working with patients and carers.

SST results and gaps in stroke care

Hanne Christensen

- 49 countries took part – 1 country pending
- 1.3 million stroke events reported - 83.1% ischemic, 12.1 % hemorrhagic
- 16% mean recurrence – need to improve the data collection and to improve secondary stroke prevention
- Media 30-day survival – 87% overall, but large differences throughout Europe
- Data sources vary across Europe – national registries; health surveillance; reimbursement data; RESQ data; single regions; estimates
- Crude incidences – significant differences in incidences across Europe
- No change in national stroke plans but more countries are having on going work, only 9 countries report nothing is happening
- 63% of countries are involving SSOs
- Prevention plans are increasing
- Audits – very few plans do audits outside the hospital environment, but this will grow, we hope when national plans mature
- Stroke unit admission – no change – 68% mean; few countries provide stroke unit care within 24 hours of admission
- Acute treatments within guideline times – access is still low
- Access to investigations in stroke units – is highly supported and recorded by NCs
- 90% of stroke units have ESD – achieved by 11
- Secondary stroke prevention - access to antithrombotic in 13 countries, anti-hypertensives in 7 countries, lipid lowering drugs 5 countries, lifestyle advice in 4 countries (based on high quality data)
- Transition plans – 3 countries (high quality data)
- Follow up – 1/49 is using a post stroke check list; follow up target met by two countries
- Fatality within 30 days less than 15% – 17 countries

Overarching targets

- Target 1: Age standardized stroke rate: 223 per 100,000. Target – reduce by 15% by 2030
- Target 2: Stroke unit as first level care. 68%. Target – greater than 90%
- Target 3: National stroke care plans. 40% Target 100%

- Target 4: Public health prevention strategies. 59%. Target 100%

Good and bad news

Good	Bad
49 countries submitted data	Continued inequity between countries - northern and western Europe are stronger than Southern and Eastern countries.
42 countries have a national stroke plan or in the process of developing one	Inadequate data quality in many countries
Increasing number/29 countries have a plan for primordial and primary prevention	Recurrent stroke and secondary prevention, and follow up
Mean European MT-rate 7.3%	Access to stroke unit care
Increasing access to rehabilitation in the stroke unit	

SAP-E Advocacy – From data to policy change

An advocacy model in Belgium
Sylvie de Raedt

Sylvie de Raedt (SDR) outlined the challenges of advocating for stroke policy change in Belgium's highly fragmented healthcare system, which operates across regions, languages and multiple levels of government. She described significant gaps in stroke care, including unequal access to stroke units and thrombectomy, as well as the absence of a national stroke registry, stroke plan, stroke code, audit system and patient experience data.

In response, the priority was to build a clear national roadmap centred on a stroke plan and registry, supported by robust data and practical actions that could unite stakeholders around a common agenda.

A key step was organising a national stroke meeting that brought together all major stakeholders, including patients, and used SST data, international examples and local experience to highlight the need for change. This was followed by a written report, debriefings with policy makers, coordinated communication, stronger collaboration across partners and greater involvement of the patient board. SDR noted that progress is often slowed by limited political interest, reluctance to invest in new registries, resistance to disease-specific planning, fragmentation and lack of time and resources.

Her main lesson was that sustained advocacy depends on continuous dialogue, clear quality indicators and professional societies coming forward not only with evidence of the problem, but with practical solutions for improvement.

Austria
Wilfried Lang

Wilfried Lang described Austria's efforts to strengthen stroke policy in a healthcare system shaped by both federal government and nine states, with separate financing arrangements that have made data linkage difficult.

A first priority has therefore been to connect data from across the stroke pathway, including stroke unit records, administrative datasets, mortality data and health insurance information. He noted that Austria is the first condition area in the country to attempt this level of linkage, reflecting a significant step towards a more complete picture of stroke care and outcomes.

Alongside this, Austria has agreed a new stroke pathway and a shared set of quality indicators covering prevention, incidence and severity, pre-hospital management, long-term mortality and morbidity, in-hospital care and post-stroke support.

The next intervention will be to implement a national platform for assessing the quality of stroke care across Austria, with the aim of identifying variation, supporting improvement and ultimately reducing complications after stroke.

Italy
Andrea Vianello

Andrea Vianello spoke from the perspective of both lived experience and national advocacy, drawing on his role as a journalist, stroke survivor and President of ALICE. He described ALICE as a federation of around 80 volunteer organisations across Italy, bringing together people with lived experience, healthcare professionals and volunteers to strengthen awareness, support and advocacy. He underlined that stroke remains a leading cause of disability and highlighted the continuing stigma that can surround stroke in Italy, reinforcing the need for stronger public understanding and better support for people affected.

He also highlighted several practical initiatives led by ALICE, including the success of the FAST Heroes campaign, which has already reached around 18,000 children with key stroke awareness messages. In addition, he pointed to the organisation's work on stroke in younger people and on spasticity, while emphasising that rehabilitation must remain central to any effective stroke strategy. Overall, his contribution showed how patient organisations can combine awareness, lived experience and advocacy to drive change across the full stroke pathway.

Slovakia
Zuzana Gdovinova

Zuzana Gdovinova (ZG) described how stroke advocacy in Slovakia began from a position of significant weakness, with poor stroke registry data, limited access to medicines and insufficient rehabilitation services. Faced with these gaps, the government initially planned an emergency network, but the stroke community successfully argued for a more appropriate solution: a dedicated network of stroke hospitals supported by published national guidelines for acute stroke care. This helped shift the discussion from a general emergency response towards a more specialised and coordinated model for stroke services.

A further step was to publish stroke data publicly in a format comparable with international reporting, increasing transparency and placing greater pressure on hospitals to improve performance. Although this initially caused concern among some hospital directors, it also created momentum for change and laid the groundwork for more structured planning. ZG noted that acute care indicators have since improved, and that broader reforms in institutional healthcare are now creating better conditions for continued progress across the stroke pathway.

Open questions for the audience: What is your top advocacy priority?

- Post stroke care (post stroke plan, access to rehabilitation, post stroke check lists, follow up, life after stroke) (26 mentions)
- Acute care (12 mentions)
- Awareness and prevention (9 mentions)
- National stroke plan (7 mentions)
- National stroke registry (5 mentions)
- Workforce (3 mentions)
- General
    - Separately financial support for primary stroke centers
    - Integrated AI and communication platform for deciscion support/image sharing
    - Stroke prevention, including multidisciplinary sectors, politicians, etc

- Quality control
- Money
- Focus groups, Patient involvement in research
- Sex differences, recurrent strokes, ICH equal focus as IS
- KPI's on acute stroke Care and post stroke care
- Working with government

Addressing the growing burden of Stroke and CVDs in Europe

Update on the EU CVH Plan and WHO resolution on stroke
Melinda Roaldsen

Melinda Roaldsen gave an update on two major policy developments with direct relevance to stroke. She explained that SAFE and ESO had actively advocated for stroke to be included in the emerging EU Cardiovascular Health Plan, including through a joint event in October and participation in the EACH meeting in December. When the European Commission published the Plan in December 2025, both organisations broadly welcomed it, recognising that its focus on prevention, care pathways, rehabilitation, innovation and inequalities could help support the development of national stroke plans across Europe.

She also highlighted the importance of the WHO resolution on stroke, which is the first WHO resolution dedicated specifically to a health condition and will be discussed at the World Health Assembly in May 2026. This was presented as a landmark step in raising stroke's profile within global health policy and creating stronger momentum for national action across prevention, acute care, rehabilitation and long-term support.

Together, these developments show that stroke now has a stronger policy platform at both European and global level, although continued advocacy will still be needed to ensure that commitments translate into implementation.

State of CVH in the European Union
Katherine de Bienassis, Health Policy Analyst
Health Division, Directorate for Employment, Labour and Social Affairs, OECD

She discussed the state of CVH in the European Union report. Much of the stroke data came from the SAP-E SST.

She emphasised that stroke places a substantial burden on both hospitals and post-acute care services across Europe, with people often requiring longer hospital stays and ongoing support after discharge. Outcomes also vary markedly between countries, with significant differences in mortality and a higher mortality rate reported among men. This underlines the uneven performance of stroke systems across Europe and the need for stronger, more consistent care pathways.

She noted that the post-stroke pathway is often where health systems fall short. Although many people survive the first year after stroke, readmission and mortality remain high, and access to rehabilitation and secondary prevention medicines is still uneven across Europe. Mental health problems, memory loss, dementia and depression were highlighted as major but often under-recognised consequences. She also stressed that hypertension remains one of the most actionable targets for stroke prevention, yet key preventive measures such as blood pressure, blood sugar and cholesterol checks are not implemented consistently. Stronger health checks, risk stratification, early intervention, monitoring and lifestyle advice are therefore essential to reduce risk and improve outcomes.

The role of primary health care in stroke prevention – in the Ukraine
Andrii Skipalskyi, Unit Lead, NCD Management
WHO Country Office in Ukraine

Andrii Skipalskyi outlined the scale of stroke in Ukraine, referring to data on admissions and mortality, and emphasised the central role of primary health care in both prevention and longer-term management. He stressed that primary care is a key leverage point for identifying risk through screening, early detection, treatment and advice, and that it becomes equally important again after stroke, when ongoing management shifts back into the community. He also noted that major risk factors such as hypertension and diabetes remain underdiagnosed and undertreated, underscoring the need for stronger prevention and follow-up.

He described a series of reforms designed to strengthen this response, including established performance indicators, a national cardiovascular screening programme for people aged 40 and over, and changes to financing and incentives within primary care. These include higher capitation rates, additional weighting for rural areas and broader efforts to improve access to affordable medicines, supported by initiatives such as mobile pharmacies and postal delivery. He also pointed to ongoing capacity-building work and the development of stroke care dashboards, which are helping to improve transparency, track performance and support accountability across the system.

Workshop: From fragmentation to continuity in the patient journey - Continuity in the chain of care, from acute care to rehabilitation and life after stroke

What are the major gaps in my national stroke system today (what is missing service, need of more cooperation, better parallel processing, etc)?

- Primary prevention
- Transitions and coordination and continuity, people getting lost – from emergency, to acute, to rehabilitation, to community
- Post acute stroke – multidisciplinary, multisectoral
- Life after stroke issues rarely addressed
- Use of checklists – acute, post-acute, post stroke
- Monitoring - registry, long-term outcomes, fragmentation
- Evidence/data – not enough or if it there is it isn't being used
- Policial Will

What priority would have the greatest impact if implemented within 2-3 years?

- Data/national registries using the SAPE KPIs
- Primary prevention focus
- Transition and rehabilitation plans, standard operating procedures – early and community rehabilitation
- Check list – pre/acute/post stroke
- Multisectoral linking – primary, emergency, medical, nursing, allied health professionals, SSOs
- Increased use of AI/integration of software

- Pathway to include full pathway of care
- Individualised care
- Multisector collaboration
- Transitional care

What might be the main barriers (political, organisational, financial) to achieve this and how could these barriers be addressed?

- Funding
- Political factors
- Care transitions
- Policiy makers to implement a mandatory national registry based on the SAP-E KPIs

Workshop: Ensuring equity in stroke care - Addressing social determinants of health to improve access, implementation of SAPE and good outcomes.

How is the status of equity in my country?

- Geography (country-level differences)
- Economic factors (regional differences)
- Social deprivation
- Inequity in EMS, acute, stroke unit, rehabilitation, prevention, follow up, continuity
- Special situations affecting equity - climate change, environmental factors, War/conflict
- Vulnerable populations – gender, vulnerable groups, education
- Data and technology - tele-stroke, integration of health and social data, analytics and access to data

Do we have data stratified by socioeconomic status, geography, or education? If not ,how can inequity be identified?

- Equity index
- Assessment of risk
- Patient needs
- Community impact

What is one concrete action your country could take within the next 12 months to address social determinants of health impacting equity and reaching the SAP-E goals?

- Technology (telemonitoring and telerehabilitation/use of data) – to see people who are at higher risk of stroke
- National registries (including socioeconomic and geographical issues)
- Standardised digital discharge summary

Day 2: Tuesday 5 May // Joint SAP-E NC & ESO East

A capacity-building strategic and collaborative partnership - SAP-E and ESO EAST
Natan Bornstein

ESO EAST has developed over the past decade as ESO's practical implementation programme for Eastern Europe and other high-gap stroke-care settings. Its strength has been building change through: country leaders, peer networks, education, RES-Q/SITS quality monitoring, benchmarking, and shared publications. Across 24 countries, ESO EAST has helped move stroke improvement from isolated local initiatives to a collaborative community focused on measurable improvements in access, quality and outcomes.

The time is now for ESO EAST and SAP-E to partner more closely because Europe already has the roadmap, targets and accountability system, but implementation remains the limiting step. SAP-E brings the strategic framework, national coordinator structure and the stroke service tracker; ESO EAST brings trusted country networks and practical know-how in high-gap settings. Together, they

can turn SAP-E objectives into country packages, training, pathway redesign and measurable gap closure before 2030.

From data to better recovery: Quality, outcomes and patient-centered innovation in stroke rehabilitation

Real-time monitoring data to transform clinical practice (RESQ, SST, institutional level: rehabilitation)

Cristina Tiu, Romania

What needs to be monitored:

- Structural indicators – stroke units, stroke protocols, neurologists
  - Who monitors – MoH, regional and hospital level, insurance systems
- Process indicators – evidence-based interventions – imaging within 24 hours, door to needle
  - RESQ+, an intelligence-based platform based on guidelines, mostly based on process indicators
- Outcome – what is the impact of care – mortality, disability at discharge
  - The data collected from RESQ+ can feed to the SST in ESOEAST

Stroke quality data still needs to improve. Hospitals must verify their data, and initiatives such as the ESO Angels awards can help strengthen data quality. Poorer resources are clearly linked to poorer outcomes.

Work with ministries of health, finance and other decision makers, including regional or local authorities, to agree quality indicators and mandate the data needed to improve care. Engagement with insurers is also essential so agreed protocols are reimbursed.

Conclusions

- Real life data are essential for tailoring stroke pathways specific for each country/region
- We need to find solutions for more data and good quality data
- We need to involve more stakeholders and to increase advocacy actions
- We need to close the loop and use the data to correct and improve the field situation.

Meeting the need, how to build quality and outcome control in rehabilitation registries

Brigit Forchhammer, Denmark

The Danish stroke register provides strong insight into acute treatment and care, but much less is known about what happens after discharge, including rehabilitation and life after stroke outcomes beyond survival.

In Denmark, municipalities are responsible for stroke rehabilitation, delivered through public and private providers, but there is limited information on quality, variation and where improvement is needed.

To develop the idea of a rehabilitation registry, the first step was to decide what should improve and what needs to be measured, with the aims of supporting national improvement, reducing inequalities and strengthening research. The registry governance will involve representatives from regions, municipalities, private providers, professional organisations and SSOs. Quality indicators of the registry should cover whether rehabilitation is individualised, timely, intensive enough, evidence-based, delivered for the right duration and supported by appropriate professional competence. Key endpoints include functional outcomes, independence and quality of life.

Where to get the data:

- Phase 1 should use existing data, including civil registration numbers, legally required discharge rehabilitation plans, diagnosis, medication, socioeconomic status and civil status.
- Phase 2 should add new data on functional status and quality of life, including PROMs.

PREMS and PROMS: the key to patient centered care
Maeva May, UK

Maeve May explained that clinical data only tells part of the story; patient evidence is also essential. PREMs capture experience, while PROMs measure outcomes.

She then outlined the UK stroke PREMs project, a pilot project with NHS England, NHS trusts, the SSO and a survey across whole pathway. The survey was designed with stroke survivors, carers, the SSO and NHS England experts, covering understanding stroke, involvement in decisions, support and return to life, including work and hobbies.

Of 27,000 surveys sent through NHS trusts and hospitals, 6,616 responses were received. Results showed that 91% felt treated with dignity and respect, but 39% were unclear about medication at discharge, 23% wanted emotional support but did not receive it, and only 28% felt supported to return to work.

In addition, PROMs from the SSNAP research showed employment falling from 15% before stroke to 6% after stroke, while 55% struggled with usual activities and 44% reported anxiety or depression.

Both the PREMs and PROMs results reinforced that there are clear gaps in life after stroke support and recovery does not stop at discharge.

For the SSO, the results showed why people seek support: emotional wellbeing, understanding stroke, daily living and independence, finance and benefits, carer support and fatigue. Many people find the SSO after three months and may need support for months or years.

PREMs data is now being used to improve pathways, identify gaps and support commissioning decisions.

Motivation, dedication and service in implementing and improving care - beyond medical care,
Dorina Dobreva, Bulgaria

Dorina Dobreva reflected on stroke care beyond clinical treatment, drawing on lived experience to show the gaps that often appear after discharge, when communication breaks down and families must navigate complex systems alone. She argued that SAP-E should be understood not only as a medical framework, but as a commitment to continuity, partnership and practical support. Examples from Bulgaria, including helplines, municipal collaboration, aphasia centres, prevention programmes and digital tools, showed how patient-led initiatives can turn policy into practical improvements for survivors and caregivers.

She emphasised that long-term outcomes depend on integrated rehabilitation, psychosocial support, patient navigation and community education as essential parts of care. Patient organisations were presented as connectors and implementers, helping to maintain continuity across the pathway. Her closing message was that success in stroke care should be measured not only by survival, but by the extent to which people are supported to rebuild their lives.

Workshops NCs and ESO East

Topic 1: Co-operation of professionals and SSO

What is the added value of SSO and good cooperation to improve the whole chain of care?

- Support patients, doctors, caregivers and volunteers.
- Help patients navigate care pathways.
- Answer questions and promote patient rights.
- Provide trusted information and advocacy.
- Address inequities through community engagement.
- Identify problems in care pathways in real time.

- Reduce burden on healthcare professionals.
- Coordinate advocacy and educational activities.
- Different agendas
- SSOs not working together – an umbrella/collaboration might be a recommendation for particular projects for example with advocacy or awareness campaigns
- How to reach all patients

Barriers to cooperation between professionals and SSO and how can they be tackled?

Barriers

Funding constraints.

- Lack of alignment and collaboration between SSOs.
- Limited government support, particularly in countries without established SSOs.
- Credibility and recognition challenges.
- Difficulty reaching and engaging patients.

Things we need to do

- Develop SSOs in countries where there are none
- Toolkit for basic, middle, advanced SSOs

Topic 2: Challenges in using real-time monitoring of rehabilitation, PREMs and PROMs - foundation to truly achieve patient centered care

How to use PREMs and PROMs to change situation – things to consider

- Consider when to do it to and what you are looking to find out – at discharge will not cover the longer-term impact of stroke
- Establish model of what is PREM and PROM which could be country adapted
- Design questions around the needs of the patient – so the outcomes that they should experience not the experience of the medication or therapy
- Involve the care giver to help with survey response
- Timing of measuring
- How to collect information. Lack of digitalization in some countries.
- Not a quality improvement tool, but assessment of situation
- important to exactly formulate questions

Real time monitoring

- Discharge questionnaire filled by patients, analysed at time intervals
- Tracking the patient after discharge – using 2–3–4 data points – such as stroke unit, post hyperacute, rehabilitation, home
- Establish PREMs & PROMs recommended by ESO/SAFE/ SAP-E and adapt for each country.
- Use P&P for quality measuring in hospital level

Barriers

- Forms are not free (not all)
- Sensitivity from both patients and doctors to express what they feel and to the results
- Inherently biased
- Patient expectations of outcomes of results may be too high
- No real time!

Topic 3: How can we tackle the patchy registries. The importance of national coverage in quality registration to achieve equitable service

What are the major gaps in your national stroke system today?

- Quality of data input and incomplete information
- Suboptimal completeness

- No real time feedback to stroke units
- Difficulties with collecting data in a structured way and with data input.
- Lack of people working with registries.

What priority would have the greatest impact if implemented within 2-3 years?

- Incentives for the data providers and uses
- Introduce mechanism to make the registry mandatory

What might be the main barriers

- Suboptimal level of digitisation of healthcare across Europe
- Need to enter data manually

How can we address this

- Continuous digitization allowing automatic extract key info to registry
- Develop minimum standards for stroke registry

Joint wrap-up by SAP-E and ESO East chairs - Going home with action points and further strategic cooperation

- The Chairs thanked all participants, speakers and workshop contributors for their active engagement throughout the meeting.
- They emphasised that, with the 2030 SAP-E targets approaching, continued work on the Stroke Service Tracker and closer collaboration with ESO EAST at European level will be essential to support implementation and shared progress.