EUROPEAN STROKE ORGANISATION

How Europe is responding to Life After Stroke

Prof Peter Kelly, President European Stroke Organisation

ELASF, 10 March 2023

Internal use

The importance of stroke is widely underestimated

Global burden of stroke

12.2 million incident strokes in 2019 (95% UI 11.0-13.6)

101 million prevalent stroke (93.2-111) (x8)

6.5 million stroke deaths (6.0-7.2) (x 0.5)

143 million DALYs (133-153) (x12)

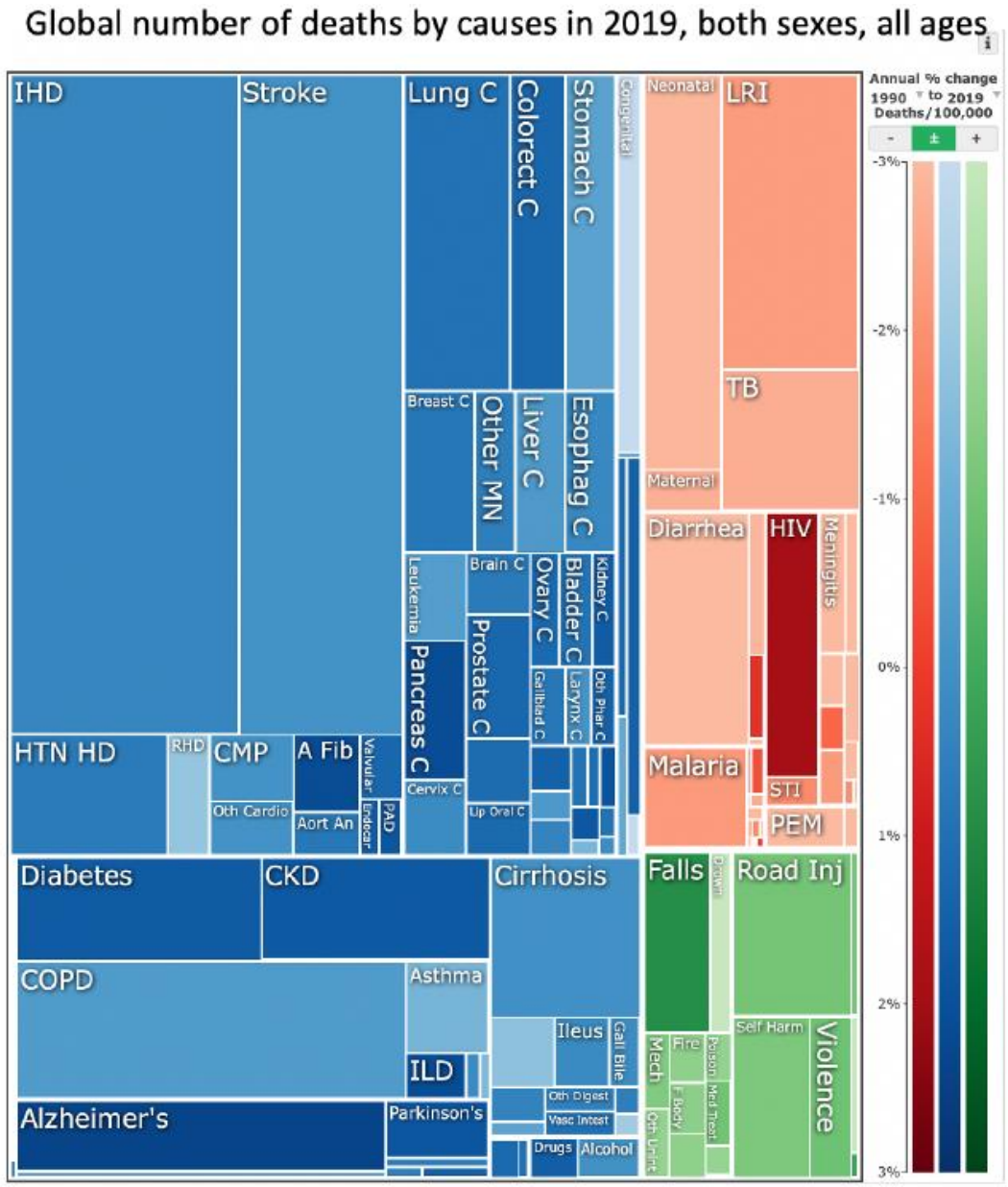
GBD Stroke Collaborators, Lancet 2021

Global burden of stroke

Leading causes of death:

CAD 16.2% (15-16.9%)

Stroke 11.6% (10.8-12.2%)



GBD Stroke Collaborators, Lancet 2021

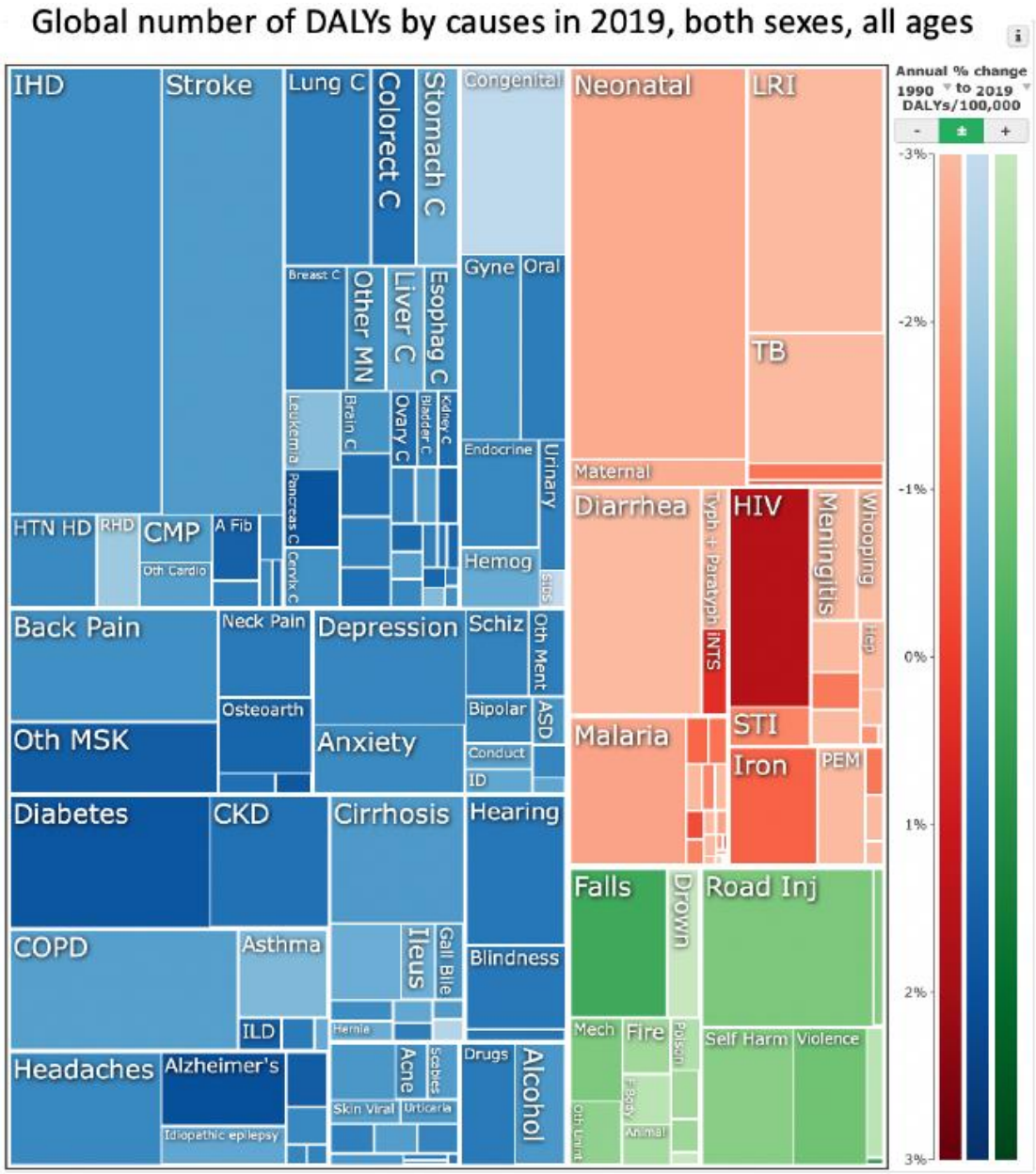
Global burden of stroke

Leading causes of death/disability:

Neonatal disorders: 7.3% (6.4-8.4)

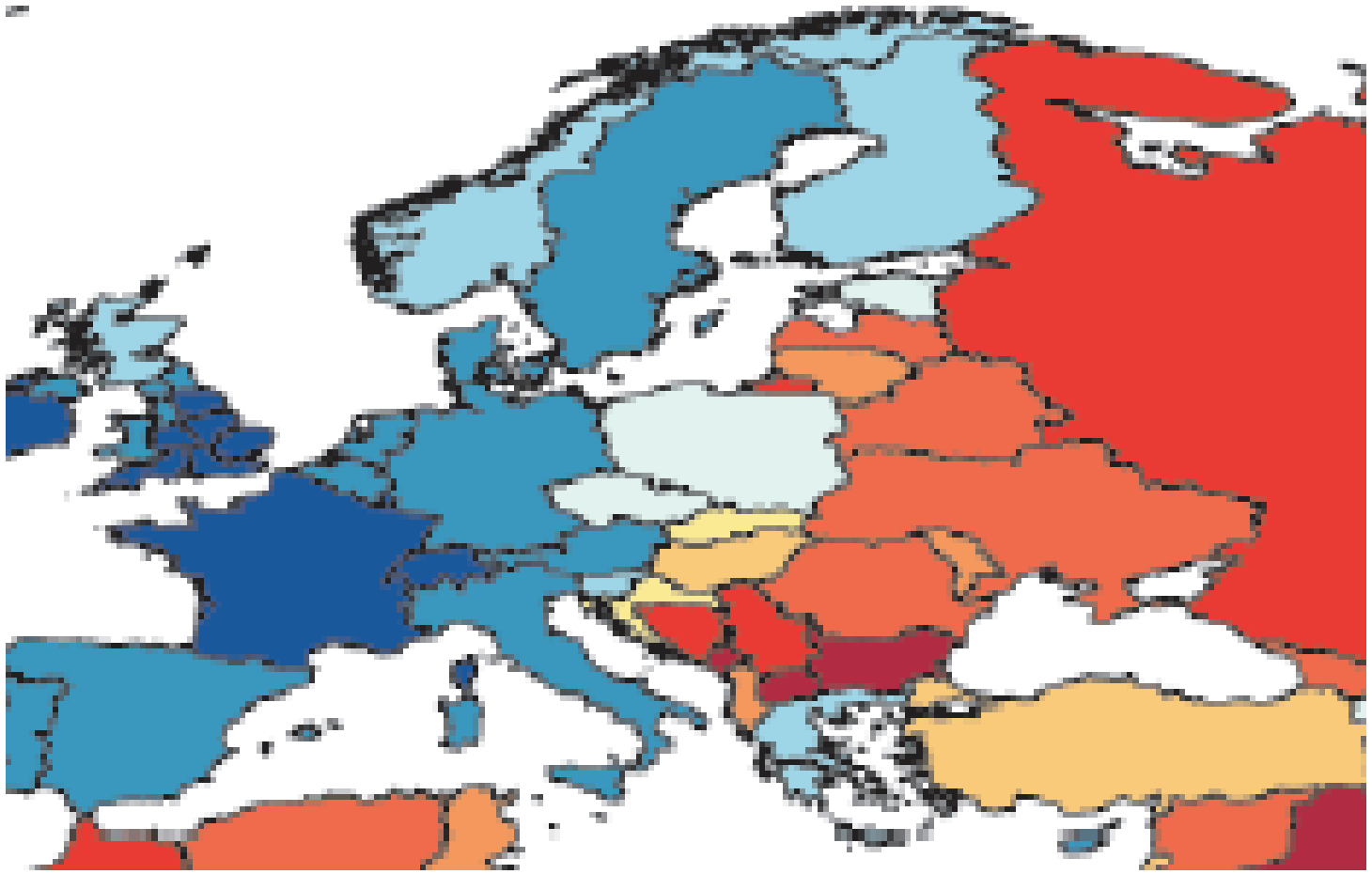
IHD: 7.2% (6.5-8)

Stroke: 5.7% (6.1-8.2)



GBD Stroke Collaborators, Lancet 2021

Widespread service gaps and inequities in stroke incidence and outcomes in Europe



Stroke incidence is 2-3 times higher in Eastern Europe

Stroke mortality and DALYs are 2-3 times worse

Source: Global Burden of Disease Stroke Collaborators, Lancet 2021

Guideline

EUROPEAN STROKE JOURNAL

Action Plan for Stroke in Europe 2018–2030

Bo Norrving[1], Jon Barrick[2], Antoni Davalos[3], Martin Dichgans[4], Charlotte Cordonnier[5], Alla Guekht[6], Kursad Kutluk[7], Robert Mikulik[8], Joanna Wardlaw[9], Edo Richard[10], Darius Nabavi[11], Carlos Molina[12], Philip M Bath[13], Katharina Stibrant Sunnerhagen[14], Anthony Rudd[15], Avril Drummond[16], Anna Planas[17] and Valeria Caso[18]; on behalf of the Action Plan for Stroke in Europe Working Group*

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The ‘road-map’ for development of stroke care in Europe

Translated in 12 languages

Norrving B, Barrick J, et al. European Stroke Journal, 2018; 3 (4): 309-336

Internal use

Action Plan for Stroke in Europe

Co-authored with SAFE

Detailed inclusion of Life After Stroke

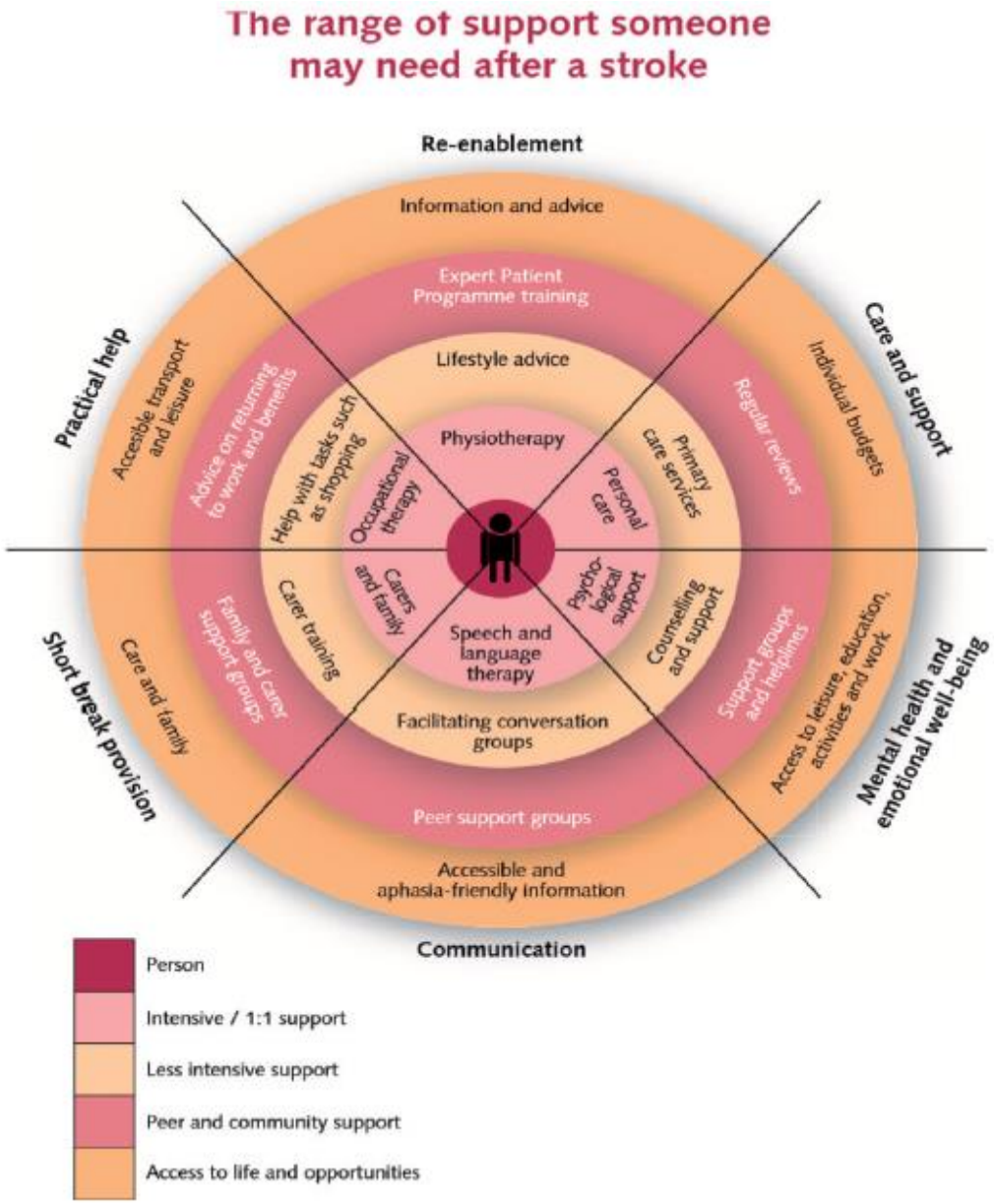
‘this area merits recognition in its own right’

‘overall, ……little evidence of holistic and coordinated support’

‘includes consideration of those who provide care’

Research and Development priority themes:

1. Investigate long-term needs
2. Develop a long-term model of best care and support
3. Define products, services, information and training for long-term support



Norrving B, Barrick J, et al. European Stroke Journal, 2018; 3 (4): 309-336

Action Plan for Stroke Europe LAS

Targets for 2030

1. Appointing government-level individuals or teams responsible for championing life after stroke and ensuring that national stroke plans address survivors' and their families' long-term unmet needs. Minimum standards set for what every stroke survivor should receive regardless of where they live.
2. Formalising the involvement of stroke survivors and carers, and their associations, in identifying issues and solutions to enable the development of best patient and support practices.
3. Establishing, through national stroke care plans, the support that will be provided to stroke survivors, regardless of their place of residence and socioeconomic status.
4. Supporting self-management and peer support for stroke survivors and their families, by backing stroke support organisations
5. Supporting the implementation of digitally-based stroke self-help information and assistance systems.

Internal use

Stroke Action Plan Europe (SAP-E) Programme

STROKE ACTION PLAN EUROPE 2018 – 2030

Collaboration of professionals and patients, ESO and Stroke Alliance For Europe

One of ESO's 4 highest priority programmes ('flagships')

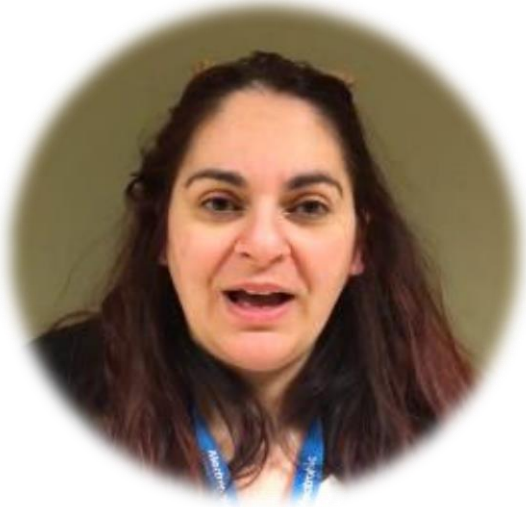
National coordinators in 49 European countries or regions, in partnership with SSOs

Coordinating office: training, KPIs, SAPE tools, support materials

Goal: With government, National Stroke plans – agreed, funded, implemented, monitored

SAP-E Programme Chairs

Hanne Christensen
Chair



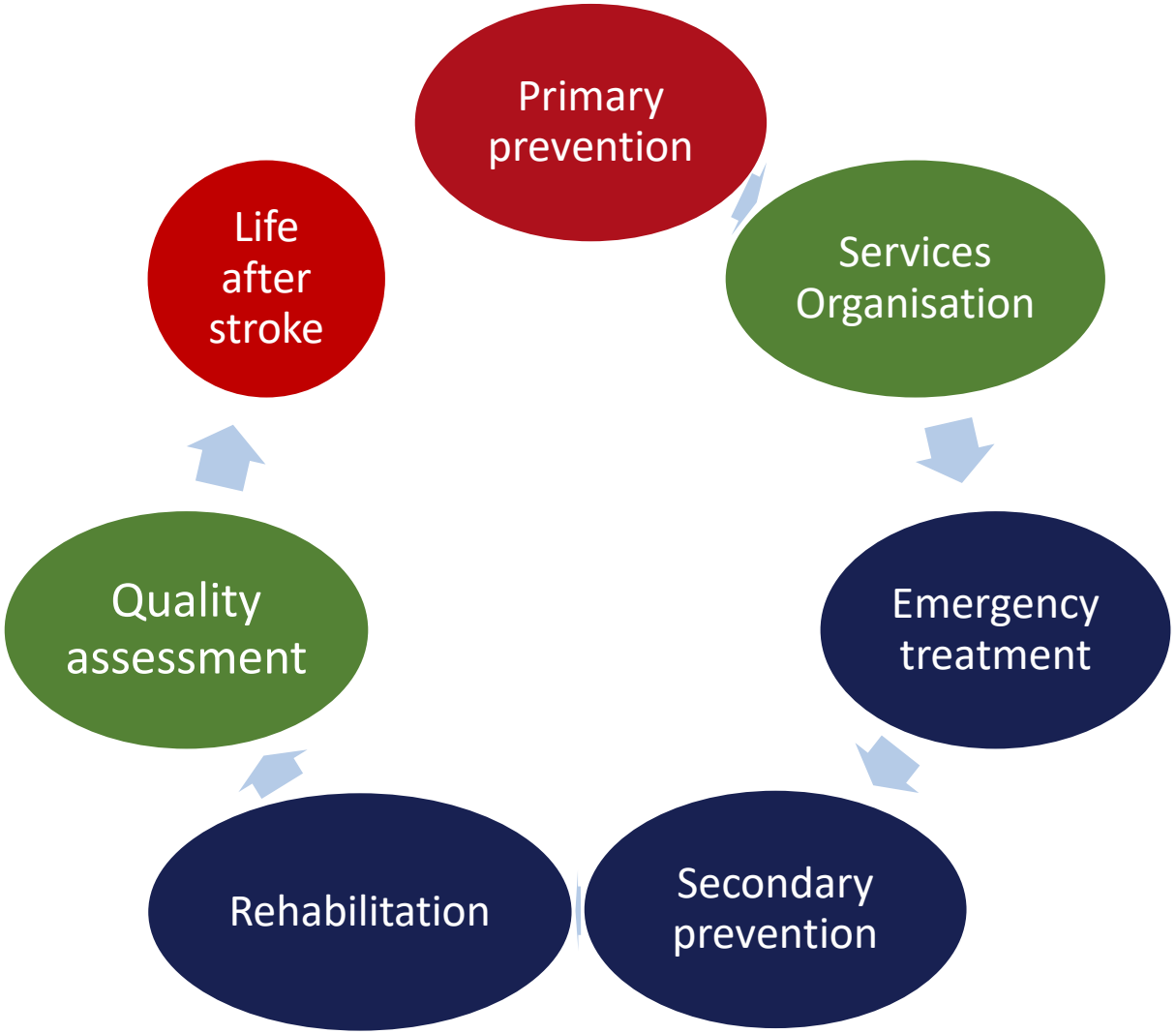
Francesca Pezzella Romana
Co-Chair

Arlene Wilkie, SAFE
Co-Chair

Internal use

SAP-E 7 domains – the entire chain of care

STROKE ACTION PLAN EUROPE 2018 – 2030



Community

– primary prevention (education, public awareness, transport, built environment, fossil fuels)

- life after stroke (late rehabilitation, public access for disability)

Hospital/clinics

- Emergency treatment
- Secondary prevention
- Early rehabilitation

Systems

- Service planning (IVT, EVT, rehab, surgery, young stroke)
- Quality assessment (registries, audit)

Internal use

SAP-E Key Performance Indicators and LAS

KPI 1: A national stroke plan defining pathways, care and support after stroke …… transition to community, and follow-up

KPI 4: Establishment of ….systems for assessing and accrediting stroke clinical services….

KPI 10: Access to secondary prevention ….

KPI 11: A binding personalised, documented rehabilitation and sector transition plan …

KPI 12: Follow-up ….including a Post Stroke Check list … functional assessment and referral for relevant interventions

SAP-E Tools – Essentials of Stroke Care

Developed by ESO Guideline Sub-committee (Chair, Prof T Steiner)

Clear list of evidence based recommendations for stakeholders

Versions for professionals/health planners and patients/public

Entire pathway of stroke care

Life after Stroke section

Aspect	Must do	Source	Type of source
Follow-up	Patients should be followed up after stroke for functional decline and new symptoms including pain, e.g. by **use of the post-stroke check list**, [35] and **referred if relevant**	[36]	EBR
Involvement, **support** and **education** of patients and relatives	**Patients and relatives should be involved** in making care plans and other planning or decisions for life after stroke and receive appropriate support and education	[36]	EBR
Driving	**Assessment** for driving ability should be performed according to local legislation	[36]	EBR
Participation (social, work, leisure-time activities)	**Individual assessment** should be performed, and r**eferral and counseling** provided when relevant	[36]	EBR
Relationships/sexuality	Education and counseling should be provided	[36]	EBR
Disability support	Care plans should be completed, and applications made in a timely manner	[36]	EBR
Advanced care planning	Advanced care planning should be made and periodically reviewed.	[36]	EBR
Transition to long-term care	**Discharge summary and care plan** should be present on admission to long term care In case of ongoing rehabilitation goals, there should be a**ccess to relevant rehabilitation services.** In case of changes in status, there should be access to reevaluation and rehabilitation	[36]	EBR

Heart and Stroke. Transitions and Community Participation Following Stroke - Section 5: Transition to Long-Term Care Following a Stroke. https://www.strokebestpractices.ca/recommendations/managing-stroke-transitions-of-care/transition-of-patients-to-long-term-care-following-a-stroke, 2020

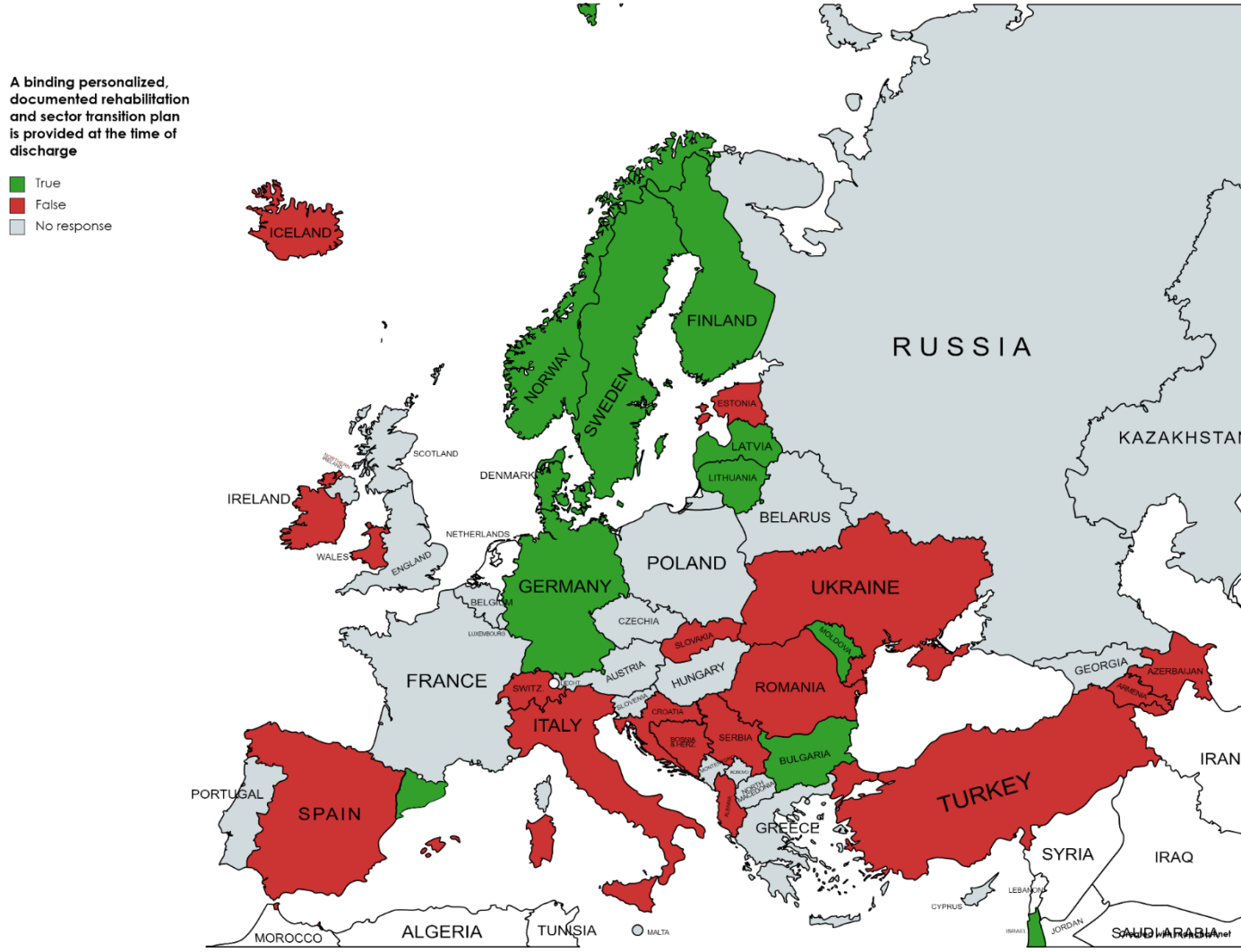
SAP-E Tools – Stroke Service Tracker

Aim to track European compliance with KPIs

National Coordinators enter summary data for their country (no patient identifiers)

First data entry Dec 2021 (2020 data)

Over time, a powerful tool to monitor and communicate stroke services



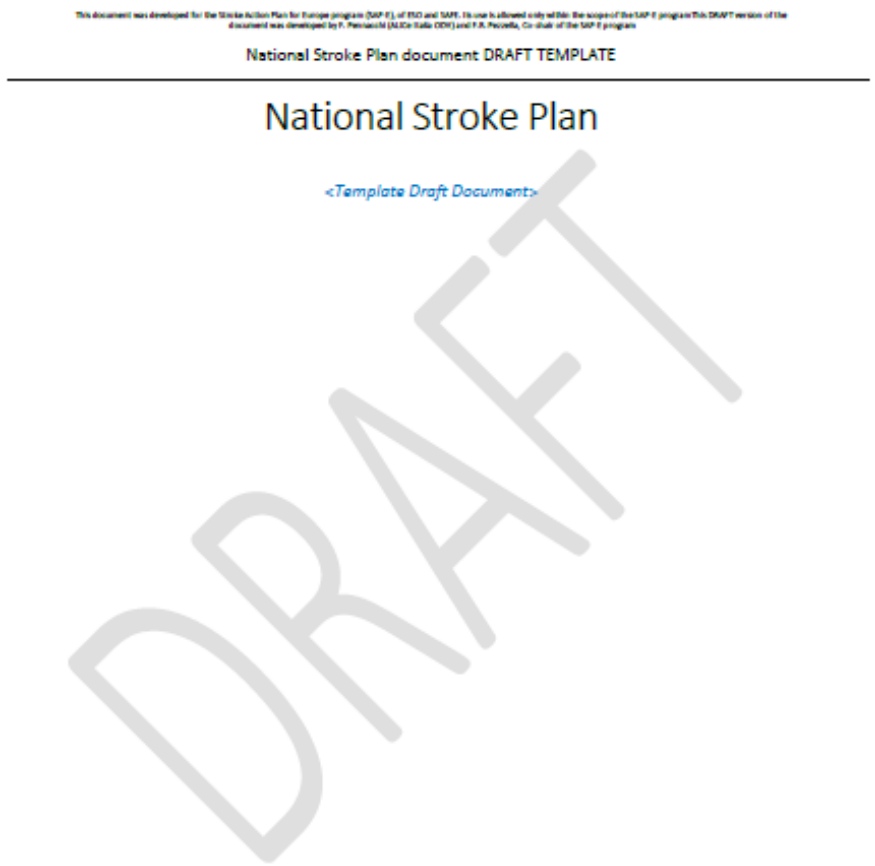
SAP-E Tools – National Stroke Plan template

A guide for European health planners to develop National Stroke Plans

Includes:
importance of patients/carers, Stroke Support Organisations as stakeholders

Patient-reported experience/outcome measures

SAP-E Key Performance Indicators for Life After Stroke



https://actionplan.eso-stroke.org/resources/available-downloads/

SAP-E Tools – Declaration

A formal statement of intent to improve stroke services, signed by the Minister of Health

Lists a commitment to meet Key Performance Indicators across entire stroke pathway including

'Appointing government-level individuals or teams responsible for championing life after stroke and ensuring that national stroke plans address survivors' and their families' long-term unmet needs'

12 countries/regions signed since 17th May 2021

https://actionplan.eso-stroke.org/resources/available-downloads/

Mailing List Sign-up

ESO EUROPEAN STROKE ORGANISATION

STROKE ACTION PLAN EUROPE 2018 – 2030

S·A·F·E Stroke Alliance For Europe THE STROKE PATIENT VOICE IN EUROPE

2022 Status Report shows big strides for stroke

ESO and SAFE have published the 2022 Status Report highlighting progress made in the past year for the SAP-E.

With this important collaboration, the SAP-E Steering Committee continues to build on its achievements from the current year.

Read The Full Status Report Here

Quick Links. Select a document here...

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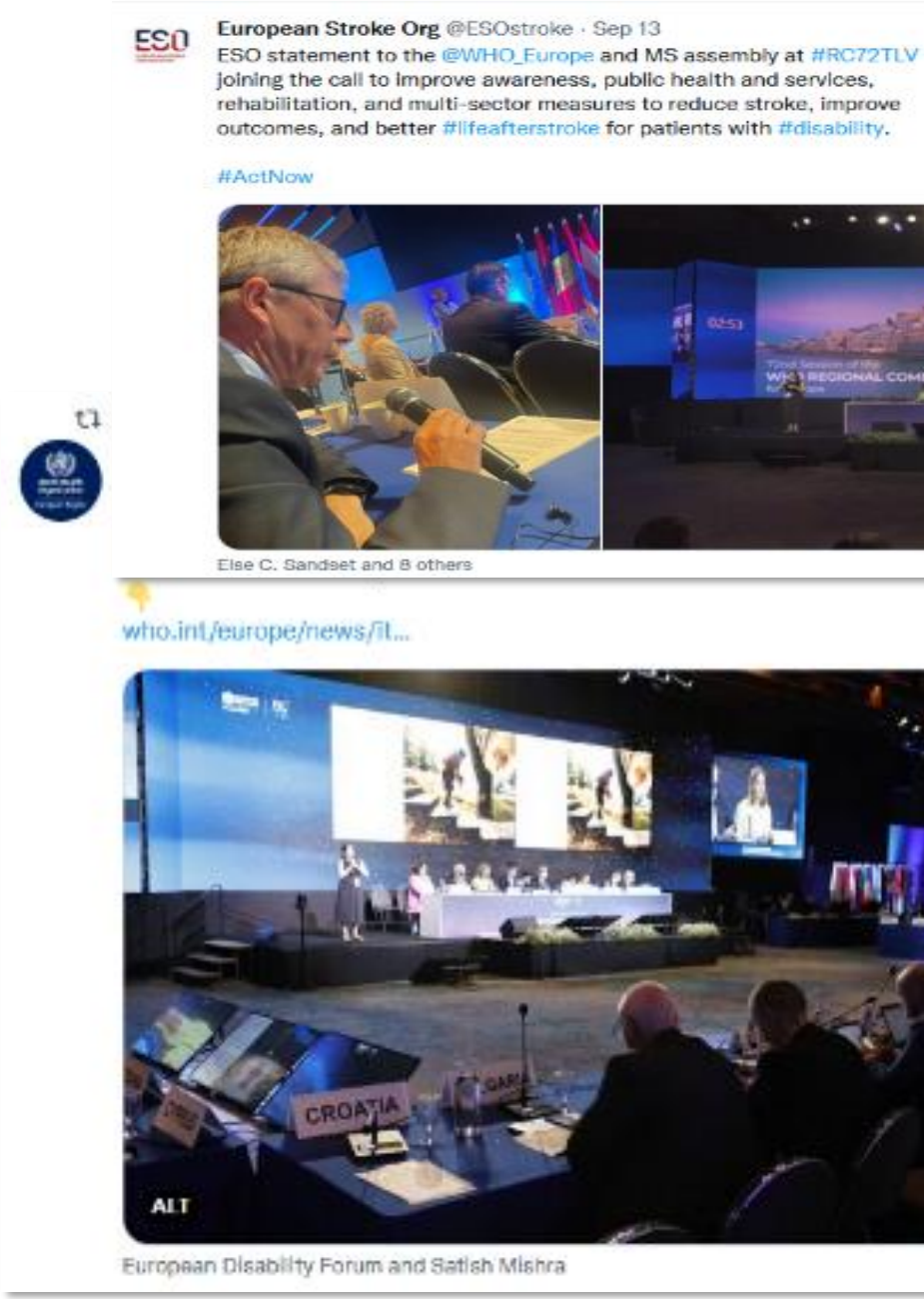
Advocacy - WHO Europe

- ESO official WHO Non-State Actor status
- Post-pandemic strategic relationship to raise profile of stroke with WHO Europe, to influence EU and national governments

72nd Session WHO Europe, September 2022:
WHO EUROPEAN FRAMEWORK FOR ACTION TO ACHIEVE THE HIGHEST ATTAINABLE STANDARD OF HEALTH FOR PERSONS WITH DISABILITIES 2022–2030

'We call for actions to ensure stroke patients' access to rehabilitation, assistive technology, support services (including peer support), and community-based rehabilitation. We emphasize the importance of developing laws, policies, and plans ……aimed at …. an environment socially and professionally inclusive for stroke patients and their families'

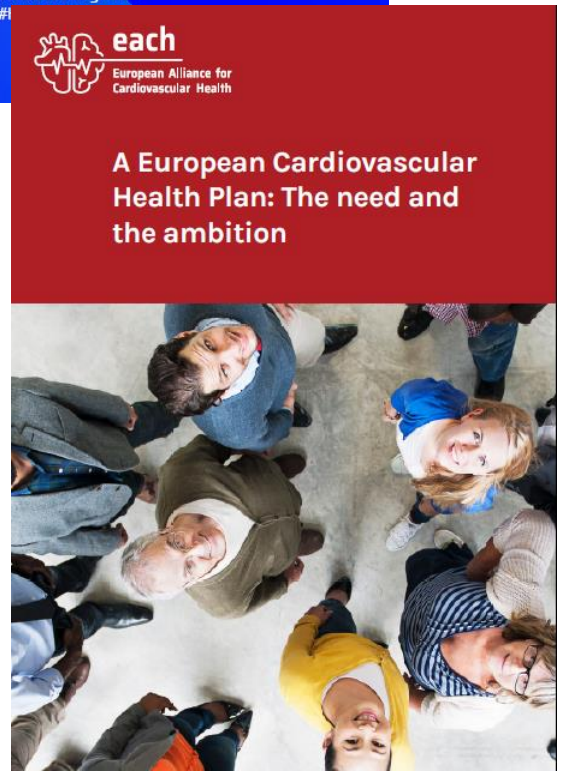


Advocacy – EU:

- ESO is working with SAFE to make stroke an EU priority

- Submissions to EU Commission for 2022 Non-Communicable Disease Initiative, Healthier Together:

'Priority 5: Supporting EU countries to …implement national plans for stroke encompassing the entire chain of care. This priority area builds on the European Stroke Action Plan 2018-2030, developed by the European Stroke Organisation in consultation with the Stroke Alliance for Europe'



- NCDI – 'a toolkit to guide' best practices (CV, DM, respiratory, brain)

- A detailed EU Policy plan for stroke needed

- ESO/SAFE partnership with European Alliance Cardiovascular Health for EU CV Plan including stroke

ESO supports:

STROKE ACTION PLAN EUROPE 2018 – 2030

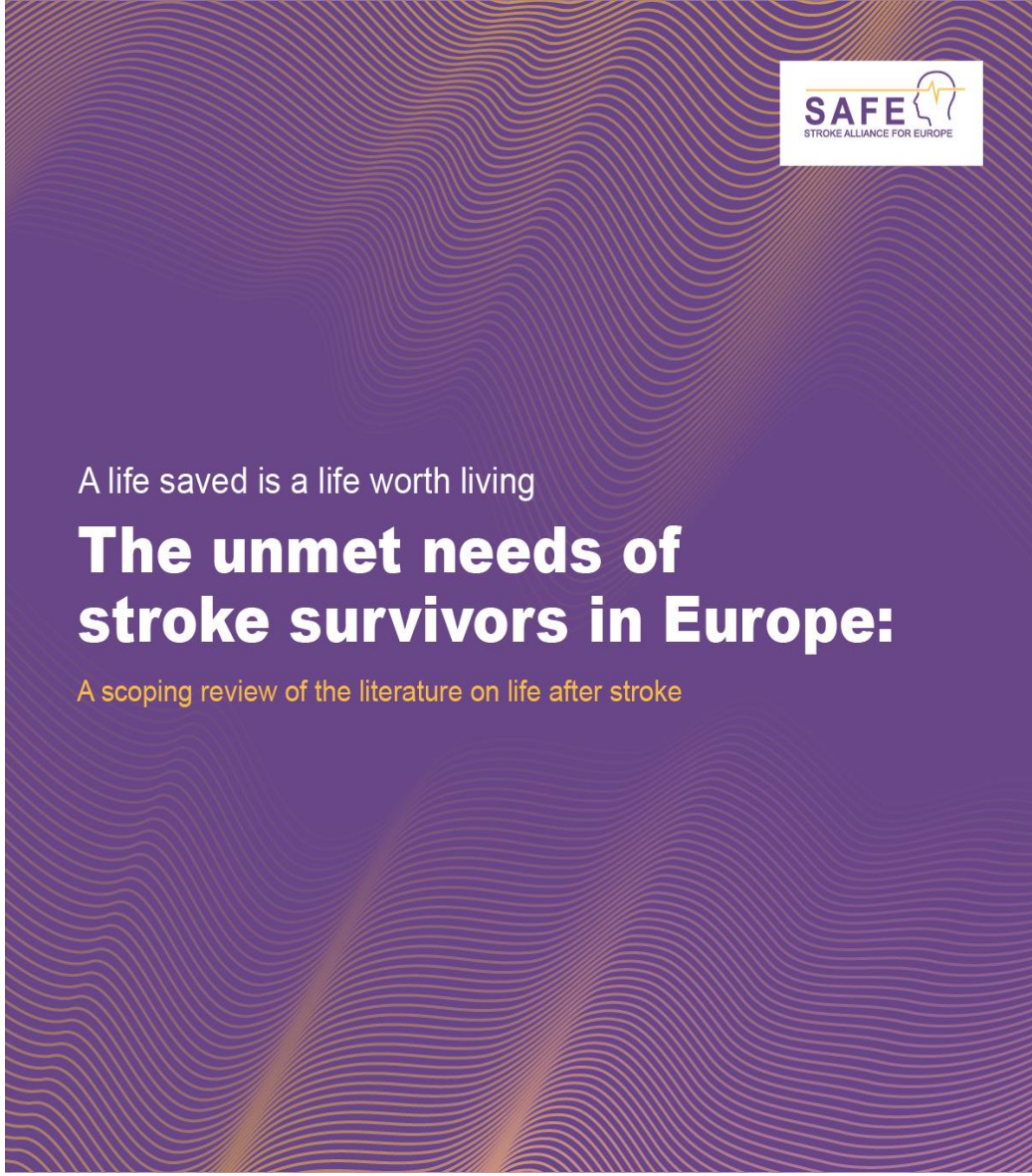
1. Long-term support for stroke survivors and carers

2. Structured follow up and access to:

- Stroke specialists
- Rehabilitation therapies
- Secondary prevention
- Services for mental and cognitive health

3. Further research into needs and service models

4. A European model of care for long-term needs after stroke



Call to action:

STROKE ACTION PLAN EUROPE 2018 – 2030

ESO and SAFE call for MOHs to SUPPORT THE STROKE ACTION PLAN FOR EUROPE

NATIONAL STROKE PLANS covering the entire pathway of stroke care

AGREED, FUNDED, IMPLEMENTED,

AND MONITORED