



World Stroke  
Organization

# Stroke Support Organization Global Mapping

## **FULL REPORT**

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On Behalf of the World Stroke Organization Stroke Support Organization Committee

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Sarah Belson, International Development Manager of the WSO, managed the project under the guidance of the WSO's Stroke Support Organization Committee co-Chairs Dr Patrice Lindsay and Ms Sharon McGowan.

Rachel Thombs, Collaboratory for Research and Innovation; Sinai Health System; Toronto, carried out the data analysis. Dr Michelle Nelson, member of the WSO Board of Directors, supervised the inception, planning and implementation of this mapping project, the first of its kind for WSO.

## Acronyms

<b>CVD</b>	Cardiovascular disease	<b>NGO</b>	Non governmental organization
<b>FAST</b>	Face Arms Speech Time	<b>SAFE</b>	Stroke Alliance for Europe
<b>LMICs</b>	Low and middle income countries	<b>SSO</b>	Stroke support organization
<b>NCDA</b>	Non Communicable Disease Alliance	<b>WSO</b>	World Stroke Organization
<b>NCD</b>	Non communicable disease		

## Foreword

### Together we are stronger

Every two seconds, someone in the world has a stroke, and for people who survive stroke, many experience chronic disabilities. Non communicable diseases (NCDs), including stroke, are indeed the world's biggest killer and cause of disability, constituting a longstanding global health crisis and a major challenge to sustainable development.

The COVID-19 pandemic has further demonstrated the urgency to invest in healthy societies, and build resilient health systems that provide essential NCD services in a timely manner, including during health emergencies. But such an ecosystem cannot be built overnight – it requires long-term vision, political leadership and sustained financing.

Civil society organizations (CSOs) play a vital role. The NCD Alliance sees the roles of civil society as the "Four A's": driving advocacy, building awareness, providing access to essential and life-saving services, and ensuring accountability. CSOs, such as stroke support organizations (SSOs), are important agenda-setters, educators, implementers and watchdogs in their respective countries and regions. The Stroke Support Organization Global Mapping Report reinforces this vital role, providing a snapshot of the nature, work and impact of the global network of stroke support organizations.

The long track record of these organizations reaffirms the value of community-led efforts by working closely with people living with NCDs, people affected by stroke and their communities, as they bring crucial insights and expertise in shaping health systems that will improve people's health outcomes. Moreover, greater collaboration between organizations working on stroke and other NCDs can only be beneficial for the promotion and implementation of common solutions.

Across the globe, this report has identified a number of stroke support organizations that are members of national NCD alliances, advocating for the reduction of shared risk factors and better stroke and NCD care. We hope the report will help map further collaboration opportunities between stroke and NCD actors and encourage joint campaigns and programmes that strengthen community responses. Together we are stronger!



President, NCD Alliance  
Todd Harper

### Strengthening global capacity to reduce the impact of stroke

The World Stroke Organization is the only global body solely focused on stroke. Our members span every region of the globe and we recognise the importance of working with members in clinical, research and community settings to reduce the global burden of stroke.

The development of stroke support organizations (SSOs) is a strategic priority for the World Stroke Organization. We focus on growing, strengthening and supporting the global SSO network, particularly in low and middle-income countries, and harnessing the voice of stroke survivors.

Over the past four years SSO membership of the World Stroke Organization has continued to grow. SSOs play a key role in our World Stroke Campaign to raise awareness of issues in stroke and are integral to our annual World Stroke Day, mobilising thousands of people to take action on stroke.

A key principle of the [World Stroke Organization Declaration on Global Prevention of Stroke and Dementia](#) is to combine community interventions, including those of SSOs, health workers and nurse educators, with pharmacological and non-pharmacological interventions for people at risk of stroke. This SSO Global Mapping Report is therefore a timely overview of how SSOs are contributing to improvements in stroke awareness and long-term care globally, and offers important insights to inform the continued development of SSOs.

We commend all the SSOs, both small and large, wherever they are in the world, on their valuable contribution to reducing the global burden of stroke and their continued efforts to mitigate the impact of the COVID-19 pandemic on patients and stroke care.



WSO President  
Marc Fisher



WSO Immediate Past President  
Michael Brainin



President-Elect  
Sheila Martins

## Executive summary

Stroke is a leading cause of death and disability globally. There are over 13.7 million new strokes each year<sup>1</sup>. There are over 80 million people currently living with the effects of stroke globally and one in four people over the age of 25 will have a stroke in their lifetime<sup>2</sup>.

There is a growing global network of stroke non-governmental organizations (NGOs), known as stroke support organizations (SSOs). SSOs are engaged in stroke prevention, awareness raising, advocacy and supporting people affected by stroke to recover and live well. Some of the larger and more established SSOs fund research, develop clinical guidelines and contribute to health professional education in stroke. This Stroke Support Organization Global Mapping Report, the first of its kind, contains data and perspectives from 92 SSOs representing 58 countries across the world for the year 2018. The key messages emerging from this data will be used to inform the ongoing development and increasing impact of SSOs as they contribute to the vision of the WSO.

- **There is considerable potential for SSOs to drive improved stroke outcomes globally.** The global network is growing, particularly in low- and middle-income countries (LMICs). They are registered organizations and involve collaboration between health care professionals and people affected by stroke.
- **SSOs are mobilizing large numbers of people affected by and engaged with stroke.** These organizations have significant numbers of volunteers and members supporting their work and benefiting from their activities.
- **SSOs are engaging beyond their local and geographic boundaries.** Membership of other organizations and alliances with shared agendas is common, and organizations in LMICs are leveraging their membership of international organizations.
- **Sustainability of human and financial resources is a major challenge and key barrier to increasing SSO impact.** The majority of SSOs do not receive government funding and while the numbers of volunteers can be a strength, the lack of paid staff in many SSOs limits their potential for large-scale impact.
- **Inadequate national strategies and policies for stroke prevention, treatment and recovery is a major challenge** that SSOs face in their work to support people affected by stroke across the stroke care pathway.
- **A lack of data on stroke incidence and prevalence, low awareness of stroke symptoms and emergency response, inadequate recognition of rehabilitation, and the limited number of support services** are further challenges for SSOs in their work to raise awareness of stroke, support treatment and rehabilitation, and assist recovery.
- **The top three solutions identified by SSOs that would aid in overcoming the challenges they face** are increased partnership between SSOs and government, clinicians and academics; improved skills in fundraising; and improved skills in advocacy and campaigning.

**The potential for SSOs to reduce the burden of stroke globally needs to be harnessed through partnerships, sustainable financing, data driven advocacy, and support for evidence based interventions.**

## Background

The World Stroke Organization (WSO) is the only global body solely focused on stroke. With approximately 3,000 individual and over 90 society members spanning every global region, WSO represents stroke specialists in clinical, research and community settings.

The WSO mission is to reduce the global burden of stroke through more effective prevention, better treatment and long-term support.

WSO's Strategic Themes 2016-2022 are to:

- Strengthen global capacity to reduce the impact of stroke;
- Build awareness and knowledge of stroke;
- Grow a robust organization.

A key priority in strengthening global capacity is the development of SSOs, by establishing, supporting and strengthening a global network, particularly in LMICs.

The global membership of the WSO includes individuals and societies. Society members are comprised of regional scientific societies and SSOs. The WSO defines SSOs as NGOs focused on advocacy and long-term stroke support. SSOs range in size, focus and membership and may be run solely by people affected by stroke, health care professionals or by a mix of people with a professional or personal interest in stroke. Globally SSOs are aiming to drive better outcomes in stroke prevention, treatment and long-term care. The WSO recognizes that SSOs are important stakeholders in global health agendas and targets. The 2013 WHO Global Action Plan for the Prevention and Control of NCDs sets out policy options to achieve reductions in global non communicable diseases (NCDs). The empowerment of patient organizations is identified as an option for implementing the plan.<sup>3</sup> Further, the 2015 WHO World Report on Ageing and Health calls for action to foster 'healthy ageing' and states that long-term care systems should be based on partnerships between governments, families, communities and care providers.<sup>4</sup>

The SSO Committee at the WSO leads the priority to support the development of SSOs globally. In the May 2019 WSO Strategy Review, the SSO Committee proposed a mapping project of all known SSOs globally.

The objectives of the mapping project are to:

- Increase understanding of the organizational background of SSOs globally;
- Obtain a snapshot of SSO service delivery, awareness and advocacy activities globally, focused on the 2018 calendar year;
- Obtain data for further analysis of the scale and reach of SSOs and their activities;
- Obtain data for further analysis of SSO capacity to produce evidence of value.

1 V. Feigin et al. Global, regional, and national burden of stroke, 1990 to 2016: A systematic analysis for the Global Burden of Disease study 2016. The Lancet Neurology

2 V. Feigin et al. Global, Regional, and Country-Specific Lifetime Risks of Stroke, 1990 and 2016. New Engl J Med 2018;379:2429-2437

3 [2013 WHO Global Action Plan for the Prevention and Control of NCDs](#)

4 WHO (2015) World Report on Ageing and Health. Geneva: WHO

## Methodology

The mapping project included a desk-based review of supporting documents such as registration certificates and organization statutes, membership application forms (in the case of WSO members), alongside internet searches of organizations' websites and social media. A questionnaire was sent by email to the identified SSOs (both members and non-members of WSO), and any gaps in the data were followed up by email and telephone.

Questionnaires were sent to 115 SSOs and 99 responses were received (86% response rate). Of these responses, one organization defined itself as a scientific society rather than an SSO, one organization stated that they were no longer operating, one organization stated that they did not want to be included in this report, and three organizations were not established until 2019. Additionally, one respondent reported that another SSO in their country was no longer operating. Of the 92 SSOs included in this mapping project, complete data is available for 86 SSOs (i.e., having provided responses to all questions). Where questions were not answered by all SSOs, the proportion of respondents is indicated.

## Scope and limitations

This is the first ever global mapping of SSOs and considerable effort was made to recruit SSOs beyond members of the WSO, including reviewing previous enquiries that WSO received, and online searches of websites and social

media. Mapping the profile and activities of 92 organizations from 58 countries, including all geographical regions of WSO membership, offers valuable insights into the work of these organizations globally. It is envisaged that this report will be updated at regular intervals and, through ongoing promotion and dissemination, will enable further identification of SSOs that are not currently known to the WSO but are working to improve stroke outcomes across the world.

There were a number of challenges encountered during data analysis and in these cases it has not been possible to draw comparisons between the respondents' data:

- Questions about Governance – this was an open-ended question and respondents gave differing levels of detail and varied descriptions of their governance structure.
- Questions about Annual Revenue – respondents reported data in either local currencies or United States dollars and are operating in differing economic contexts.
- Questions about Revenue Source – this was an open-ended question and respondents gave varied descriptions of their revenue by source. Respondents were asked a subsequent question about whether they received government funding, however this was not broken down by type (e.g., grants, commissioning).

Analysis of why some activities are more frequently reported in particular regions, and assessment of the quality of SSO activities, are beyond the scope of this report. However, this report contains data for further analysis of the scale and reach of SSOs and their activities, and data for further analysis of SSO capacity to produce evidence of value.



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# Chapter 1

## The profile of SSOs globally

There are significant differences between SSOs globally, most notably in the size of the human and financial resources available to them. Campbell and Fowler's organizational framework informs the SSO capacity building activities delivered by the WSO, with a focus on three main areas of organizational capacity:<sup>5</sup>

- Internal structure and the capacity to be;
- Programme performance and the capacity to do;
- External linkages and the capacity to relate.

This framework was utilised in categorising the data included in this report.

Capacity Domain	SSO Data Categories
Internal structure	Legal status Founder Membership status
Programme performance and capacity	Number of paid staff Number of volunteers Access to government funding
External linkages	Relationships with other organizations Websites Social media

## Overview

The report is divided into three chapters. The first focuses on the profile of the global network of SSOs. The second chapter provides a closer look at the focus of SSOs and their activities across the stroke care pathway and their involvement in research, as well as highlighting stories of success. The third chapter focuses on challenges, including gaps in data collection, and possible solutions and actions to address these challenges. It contains recommendations for ongoing support for the work of SSOs globally.

<sup>5</sup> Fowler, A. Goold, L. and James, R (1995) Participatory Self Assessment of NGO Capacity. Occasional Papers Series No: 10. INTRAC

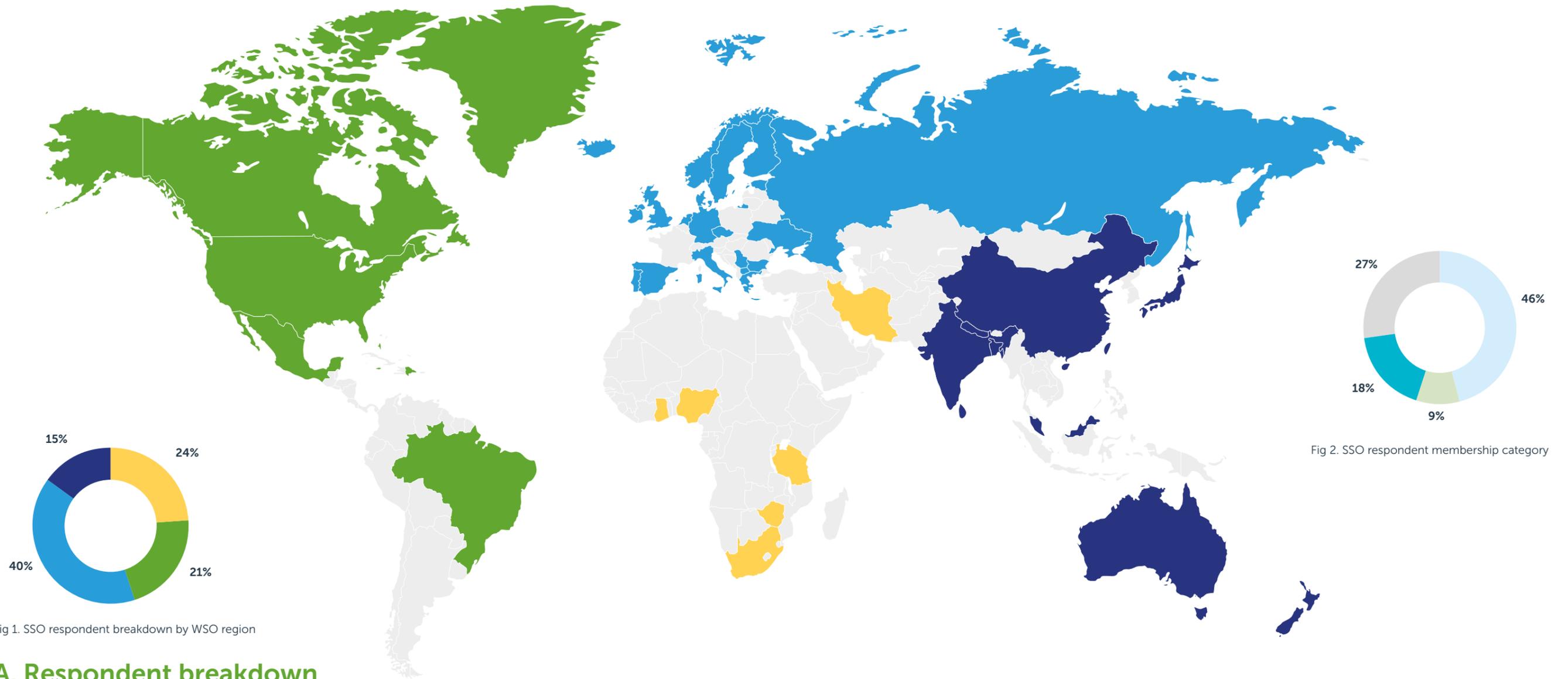


Fig 1. SSO respondent breakdown by WSO region

Fig 2. SSO respondent membership category

## A. Respondent breakdown

WSO members (including SSOs) are grouped into four regions:

- Sub-Saharan Africa/Middle East/East Mediterranean
- Americas
- Europe
- Asia/Oceania

The region with the highest number of respondents in this report is Europe (40%, 37/92), followed by Sub-Saharan Africa/Middle East/East Mediterranean (24%, 22/92), Americas (21%, 19/92), and Asia/Oceania (15% 14/92).

Two of the SSOs in this report are regional alliances, the Stroke Alliance for Europe (SAFE) and the Latin American and Caribbean Stroke Network, with society rather than individual members.

Respondent SSOs fell into four categories for membership in 2018:

- Member of WSO 46% (42/92)
- Member of SAFE 18% (17/92)
- Member of WSO and SAFE 9% (8/92)
- Non-member of WSO or SAFE 27% (25/92)

## Genesis

Respondent SSOs in their current legal form have a history spanning 57 years (1951 to 2018). However, some have a much longer history, having emerged from older organizations, such as the Stroke Association in the UK (1899). Since 2010 there has been significant growth in the number of new SSOs established. Over half (53%, 49/92) of the SSOs in this report were founded between 2010 and 2018, with the most significant growth in this period in the Sub-Saharan Africa/Middle East/East Mediterranean region.

- In Sub-Saharan Africa/Middle East/East Mediterranean, the SSOs were founded between 1980 and 2018. 86% (19/22) were founded between 2010 and 2018, with over a third (36% 8/22) founded between 2014 and 2015 alone.
- In the Americas, the SSOs were founded between 1951 and 2018, with over half (58%, 11/19) founded between 2010 and 2018.
- In Europe, the SSOs were founded between 1966 and 2018, with just less than a third (32%, 12/37) founded between 2010 and 2018.
- In Asia/Oceania, the SSOs were founded between 1980 and 2017, with half (50%, 7/14) founded between 2010 and 2018.

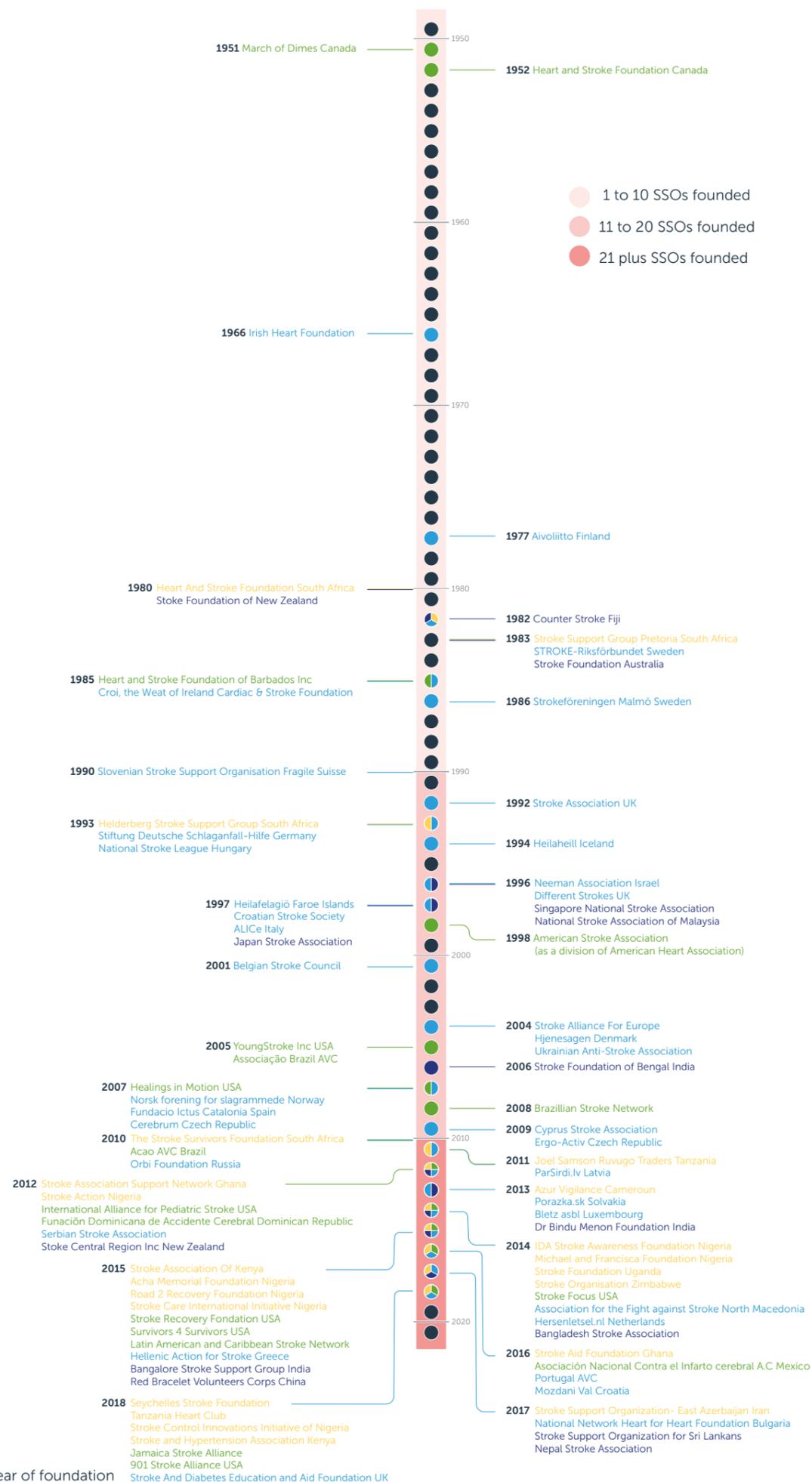


Fig 3. Year of foundation

## B. Organization structure

Data gathered on legal status, founder and membership status increases our understanding of the internal structures of the SSOs.

### Registration (Legal status)

Registration as an NGO is one important part of an organization’s journey. While NGOs do not necessarily have to register to carry out their activities, the legal status acquired under national law through registration, may be a requirement to undertake certain activities. These activities may include the ability to engage at an official level and to access government funding. Underscoring the importance of NGO registration on the global stage, a criterion for becoming a SSO member of the WSO and of the European alliance SAFE, is that the organization is registered. Across the WSO membership regions, all SSOs in this report (92/92) are registered with an authority in their country. Although it is recognized that there are different criteria for registering officially as an NGO in each country, this process requires the organization to meet specific obligations set by a national authority to demonstrate that it is a formal legal entity. These obligations may include: proof of good governance and financial management, auditing and annual reporting, all of which require the organization to have established systems and procedures.

### Founder

The number of respondent SSOs founded by people affected by stroke (45%, 40/89) and those founded by health care professionals (40%, 36/89) is similar. Notably, 15% (13/89) of the SSOs were co-founded by people affected by stroke and health care professionals.

There are respondent SSOs in all regions that reported being co-founded by people affected by stroke and health care professionals. In Sub-Saharan Africa/Middle East/East Mediterranean, an equal number of respondent SSOs were founded by people affected by stroke (45%, 9/20) and by health care professionals (45%, 9/20), while 10% (2/20) were founded by both. In Europe, nearly half (47%, 17/36) were founded by people affected by stroke, over a third by health care professionals (36%, 13/36) and 17% (6/36) by both. In the Americas, 58% (11/19) were founded by people affected by stroke, which is the highest of all regions, just under a third (31.5%, 6/19) by health care professionals and 10.5% (2/19) were founded by both. In contrast to the other regions, in Asia/Oceania, 57% (8/14) were founded by health care professionals and 21.5% (3/14) by people affected by stroke. However, again in this region there are SSOs (21.5%, 3/14) founded by both.

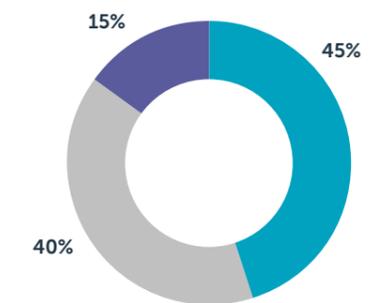


Fig 4. SSO founder

- People effected by stroke
- Health care professionals
- Co-founded

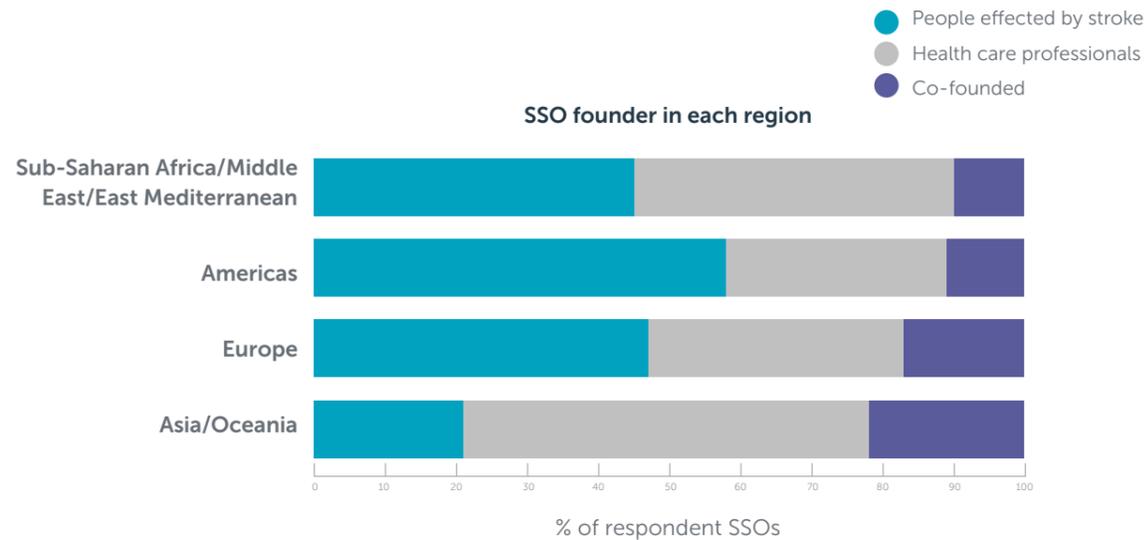


Fig 5. SSO founder by region

Therefore, given the various ways SSOs were founded, the common label of SSOs as ‘lay’ or ‘patient organizations’ is not an entirely accurate description. Health care professionals that were involved in establishing SSOs may still be involved in their management and day to day activities. This also highlights existing, widespread collaboration between health care professionals and people affected by stroke, and suggests the potential to further leverage this collaboration to drive improved stroke outcomes. The total number of respondent SSOs (55%, 49/89) founded or co-founded by health care professionals is an indication of the value that health care professionals see in collaborating with people affected by stroke.

### Membership status

Nearly two thirds of the SSOs defined themselves as a membership organization (64%, 59/92). The overall majority of the SSOs are comprised of individual members, with only the regional organizations, SAFE and the Latin American and Caribbean Stroke Network, reporting that they have society members. The questionnaire did not ask whether membership was paid or unpaid. For respondent SSOs with individual members, 53% (29/55) have 200 or more members.

- In Sub-Saharan Africa/Middle East/East Mediterranean, 59% (13/22) of SSOs reported being a membership organization, and over one third of these (38%, 5/13) have 200 or more members.
- In the Americas, 47% (9/19) of SSOs reported being a membership organization. For respondent SSOs with individual members, just under a quarter (23.5%, 4/17) have 200 or more members.
- In Europe, 70% (26/37) of SSOs reported being a membership organization. For respondent SSOs with individual members, 46% (16/35) have 200 or more members.
- In Asia/Oceania, 86% (12/14) of SSOs reported being a membership organization and 42% (5/12) have 200 or more members.

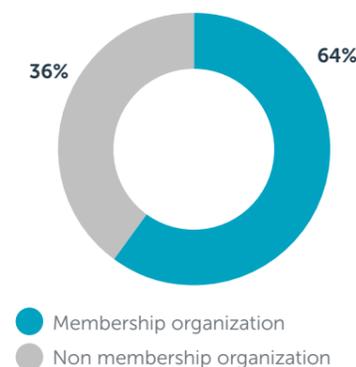


Fig 6. SSO membership status



**53%** of SSOs with individual members have 200 or more

The fact that many SSOs have members highlights the potential reach of the SSO network, beyond the formal structure of the organization and into communities and households.

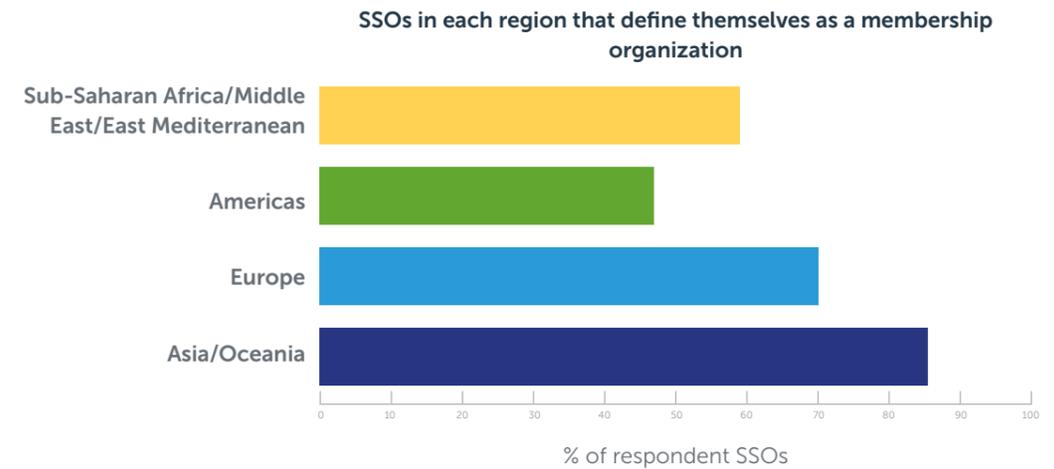


Fig 7. SSOs defined as a membership organization by region

### The percentage of SSOs by region with 200 or more members



Fig 8. SSO member numbers by region

“ Being in the Caregivers’ Support Group of the Singapore National Stroke Association (SNSA) has brought me to meet other caregivers. We enjoy the support and sharing of experiences with one another. We hope that there will be more public awareness of stroke and the important role that SNSA plays in reaching out to the stroke survivors and caregivers ”

Jane Koe, caregiver to her husband, Alan Koe who had a stroke in 2016, Singapore

## C. Organization resources

The levels of staffing, volunteers and financial resources available to SSOs are important to the organization’s capacity to deliver activities to drive improved outcomes in stroke prevention, treatment, rehabilitation and recovery. Without people and sustainable funding, many SSOs will struggle to have a measurable impact.

### Paid Staff

Over half (57%, 52/91) of the respondent SSOs reported having paid staff. However, this is often a small number (between one and five), limiting the scale of activities the SSO is able to implement and risking overdependence on this small number. Nearly half (47%, 24/51) of the respondent SSOs have only one to five paid staff. This reflects head count and not full time equivalent.

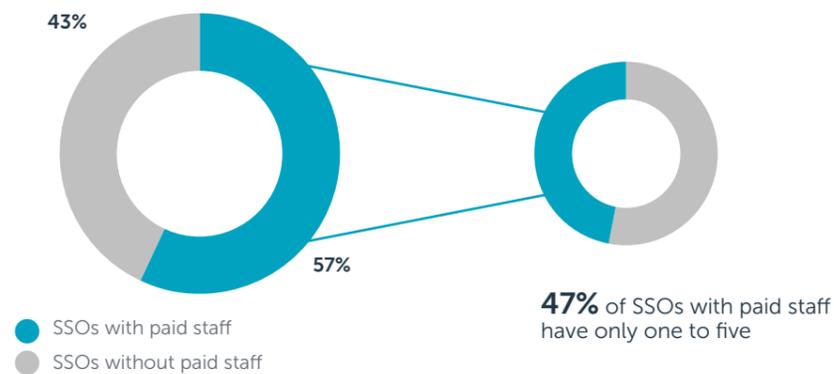


Fig 9. SSOs with paid staff

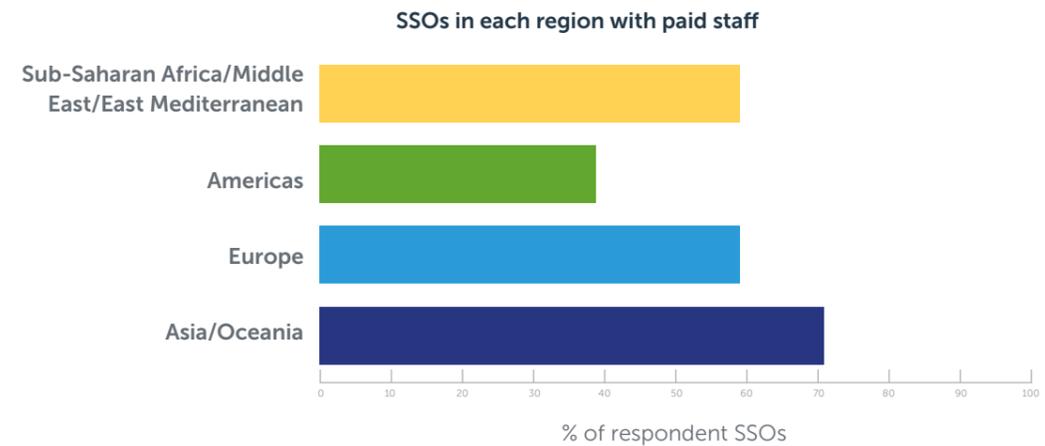


Fig 10. SSOs with paid staff by region



Fig 11. SSOs with one to five paid staff by region

“ As a result of ongoing dialogue with Stroke Action Nigeria, stroke care is now included in the national Multisectorial Action Plan for the control and prevention of non-communicable diseases. Stroke survivors will also now be included in the Anambra State Stroke Insurance Scheme from March 2021 ”

Dr Simeon Belonwu, Policy Lead, Anambra State Health Insurance Agency, Nigeria

In Sub-Saharan Africa/Middle East/East Mediterranean, 59% (13/22) of SSOs reported having paid staff. However, where data was shared, 67% (8/12) in this region have only one to five paid staff. In the Americas, over one third of the respondent SSOs reported having paid staff (39%, 7/18). However, 43% (3/7) of these have only one to five paid staff. In Europe, 59% (22/37) of SSOs reported having paid staff. However, 41% (9/22) of these have only one to five paid staff. In Asia/Oceania, 71% (10/14) reported having paid staff, yet half of these (50%, 5/10) have only one to five paid staff.

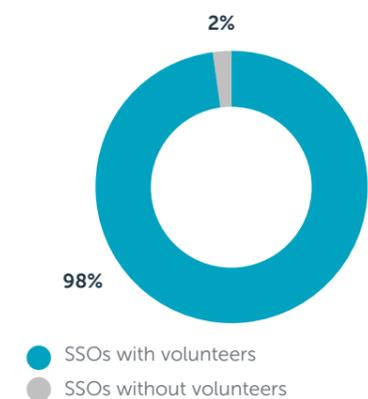


Fig 12. SSOs with volunteers

## Volunteers

The vast majority of respondent SSOs (98%, 87/89) utilize volunteers to deliver stroke awareness and support activities. In Europe and Asia/Oceania, all respondent SSOs reported having volunteers, and only a handful of respondent SSOs in Sub-Saharan Africa/Middle East/East Mediterranean and the Americas reported not having volunteers (1/20 and 1/19 respectively). Where reported, 39% (33/85) of respondent SSOs have 50 or more volunteers, and 12% (10/85) have 500 or more volunteers. It should be noted that respondents were only asked how many volunteers they had and not whether the number given represents a full time equivalent.

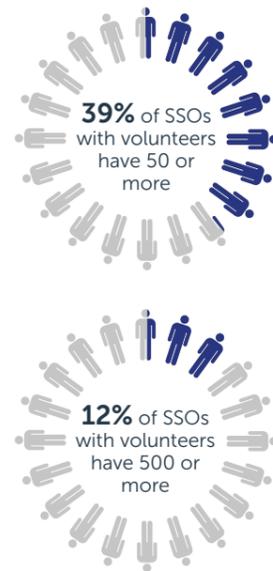


Fig 13. SSO volunteer numbers

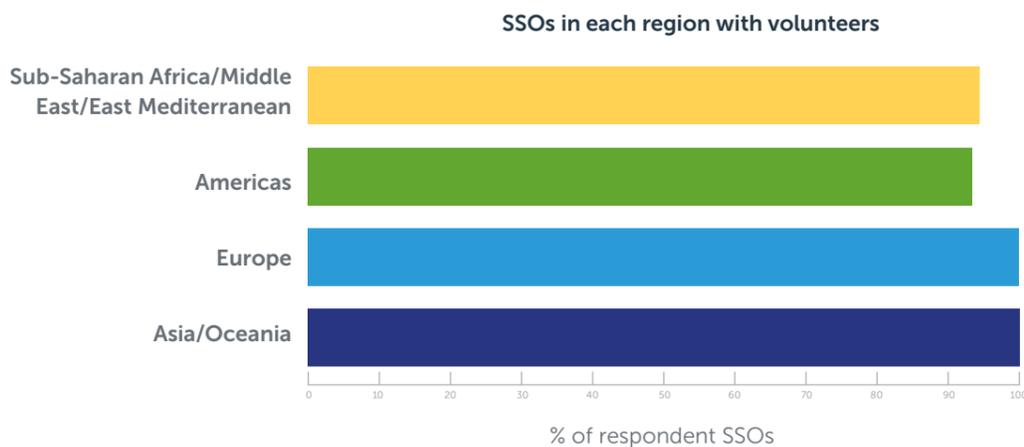


Fig 14. SSOs with volunteers by region

- In Sub-Saharan Africa/Middle East/East Mediterranean, 95% (20/21) of respondent SSOs reported having volunteers. However, only one SSO has 50 or more volunteers.
- In the Americas, 94% (17/18) of respondent SSOs reported having volunteers. 47% (8/17) have 50 or more volunteers and nearly a quarter (23.5%, 4/17) have 500 or more volunteers. Some SSOs have extraordinary numbers of volunteers involved in their work, such as the American Stroke Association with 40 million volunteers and Heart and Stroke Foundation Canada with 30,000 volunteers.
- In Europe, 100% (36/36) of respondent SSOs reported having volunteers. Where data is available, nearly half (47%, 16/34) have 50 or more volunteers and 12% (4/34) have 500 or more volunteers.
- In Asia/Oceania, 100% (14/14) of SSOs reported having volunteers. 57% (8/14) have 50 or more volunteers and 13% (2/14) have 500 or more volunteers. Of note is the Red Bracelet Volunteer Corp in China that has 32,794 volunteers.

The percentage of SSOs by region that have 50 or more and 500 or more volunteers

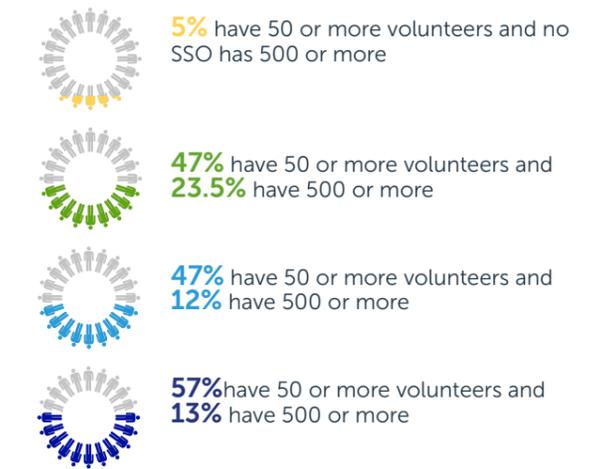


Fig 15. SSO volunteer numbers by region

SSOs across the world are utilizing volunteers to implement their work and in many cases the organization relies more heavily on volunteers than paid staff. While engaging volunteers provides a range of opportunities for organizations to extend activities, campaign and fundraise, SSOs also need to consider volunteer management, recruitment and retention, and whether volunteers are being engaged appropriately and effectively.

“ The Brazilian Stroke Network changed the history of stroke in Brazil. The organization of stroke care is our greatest model of success and the partnership with the Brazilian Stroke Network was fundamental to this

José Eduardo Fogolin de Passos, Past Director of Specialized Attention, Ministry of Health, Brazil

”

### INSIGHT

The data highlights that the ability of an SSO to have paid staff is not solely dependent on access to government funding. The most striking example of this is in the Sub-Saharan Africa/Middle East/East Mediterranean region where even though only 5% (1/22) of SSOs reported receiving government funding, 59% (13/22) have paid staff. However, of the SSOs in this region, that have paid staff the large majority, 69% (9/13), have 10 or less.

Even though only just over a quarter (27%, 5/18) of respondent SSOs in the Americas reported receiving government funding, 39% (7/18) have paid staff. The pattern is the same in Europe, as even though 41% (15/37) of SSOs reported receiving government funding, well over half (59%, 22/37) have paid staff. Following this pattern again in Asia/Oceania, only 43% (6/14) of SSOs reported receiving government funding, but 71% (10/14) have paid staff.

65% (17/26) of the SSOs that reported receiving government funding were founded before 2000.

## Government funding

Under one third (29%, 26/91) of respondent SSOs reported that they receive some government funding. However, it should be noted that there is considerable variation in the scale and type of government funding that SSOs receive. Types of government funding can include direct programme funding or commissioning and it can be accessed at national and regional (county or state) level. Government funding may also be time-bound project or programme specific funding. The questionnaire did not ask for details on type of government funding, however the responses included: funding from state and federal governments for specific programmes, government grants, government research funding and government contracts.

The majority of SSOs do not receive any form of government funding. Even in Europe and Asia/Oceania, where SSO receipt of government funding is highest, less than half of the respondent SSOs reported receiving it.

- In Sub-Saharan Africa/Middle East/East Mediterranean, government funding for SSOs is the lowest across all regions with only one organization, Heart and Stroke Foundation South Africa, reporting receiving it.
- In the Americas, just over a quarter of respondent SSOs (27%, 5/18) reported receiving government funding.
- In Europe, 41% (15/37) of SSOs reported receiving government funding.
- In Asia/Oceania, 43% (6/14) of SSOs reported receiving government funding.

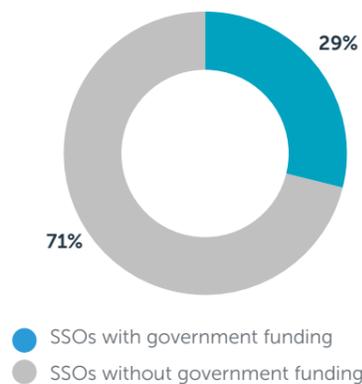


Fig 16. SSOs with government funding

### INSIGHT

Over half (52%, 13/25) of the SSOs receiving government funding were founded by people affected by stroke, while SSOs established by health care professionals account for just over one third (36%, 9/25) of the SSOs receiving government funding.

Looking at which SSOs reported having paid staff according to founder type, there was not a big difference between those founded by health care professionals (41%, 21/51) and those founded by people affected by stroke (43%, 22/51).

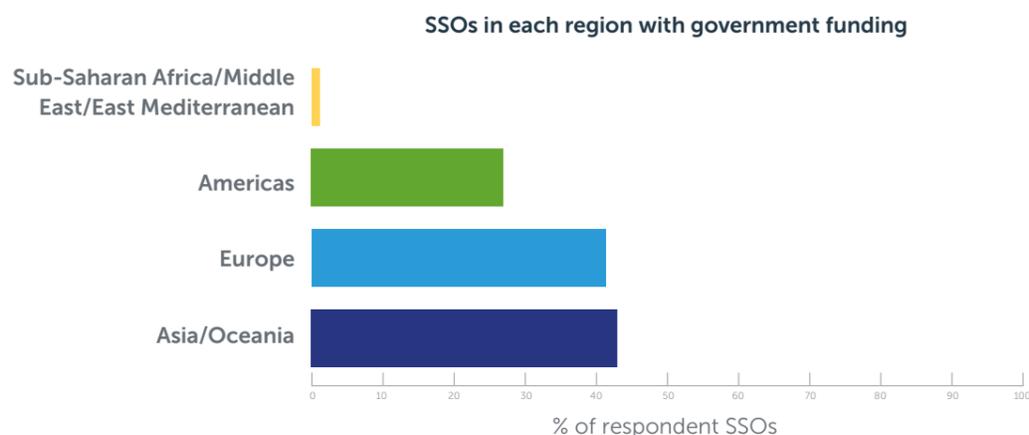


Fig 17. SSOs with government funding by region

## D. Organization linkages

The ability of SSOs to raise their profile and increase their visibility is key to achieving their mission. The profile, stakeholder relationships, and communication skills and strategies of SSOs all have an impact on their capacity to influence, advocate and raise funds. Efforts towards this include seeking connections and building networks with other organizations at the local, regional, national and international level. Additionally, a digital presence is becoming increasingly necessary to reach beneficiaries, policy makers and potential donors or funders.



93% of the SSOs are a member of at least one other organization

### Alliances

93% (86/92) of SSOs reported being a member of at least one other organization, such as an alliance or network organization.

- In Sub-Saharan Africa/Middle East/East Mediterranean, 95% (21/22) of SSOs reported being a member of at least one other organization. In this region, these organizations include the World Stroke Organization, NCD Alliance at the global and national level, World Hypertension League, African Heart Network, Africa Palliative Care Association, World Federation of Public Health and national disability organizations. Notably, all 21 of these SSOs are members of at least one international organization, with over half (52%, 11/21) reporting being a member solely of international organizations.
- In the Americas, 84% (16/19) of SSOs reported being a member of at least one other organization. In this region, these organizations include the World Stroke Organization, American Stroke Association, Chronic Disease Prevention Alliance, National Health Charities Coalition of Canada and Northern California Stroke Association. Again, all of these SSOs (16/16) are members of at least one international organization, with 81% (13/16) reporting being members solely of international organizations. This region also has the most number of SSOs that reported not being members of any other organization (16%, 3/19).
- In Europe, 92% (34/37) of SSOs reported being a member of at least one other organization. In this region, these organizations include World Stroke Organization, Stroke Alliance for Europe, European Stroke Organisation, Aphasia International Association, Global Heart Hub, World Heart Federation, European Patients Forum, Brain Injured People and Families European Confederation, International Brain Injury Association, European Brain Injuries Society, national NCD Alliances and national disability organizations. 41% (14/34) of SSOs in this region are a member of at least one international organization, with 12% (4/34) reporting being members solely of international organizations. Well half (59% 20/34) are members of only national or regional organizations.
- In Asia/Oceania, 100% of SSOs (14/14) reported being a member of at least one other organization. In this region, these organizations include World Stroke Organization, Asia Pacific Stroke Organisation, NCD Alliance, Australian Chronic Disease Prevention Alliance, Australian Stroke Coalition and Federation of Primary Health Aotearoa. All SSOs (14/14) in this region are a member of at least one international organization, with 64% (9/14) reporting being members solely of international organizations.

**INSIGHT**

A large majority of the SSOs included in this report are themselves a member of at least one membership organization, and in all regions except Europe, over half of the SSOs are members solely of international organizations. In Europe, as might be expected given the presence of some well established regional alliances, over half the SSOs are members of only a national or regional organization. This data indicates that many SSOs are reaching beyond their borders to network and collaborate with stroke and NCD focused organizations globally.

SSO membership of at least one other organization

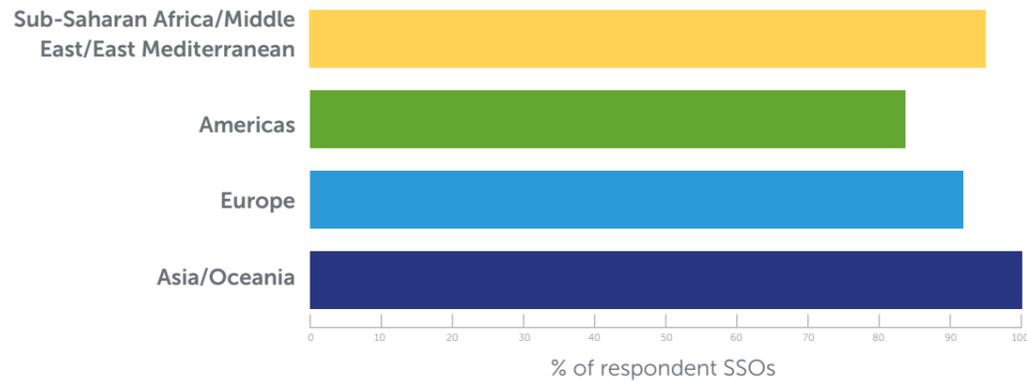


Fig 18. SSO membership of at least one other organization by region

The percentage of SSOs by region that are members solely of international organizations



Fig 19. SSO membership of international organizations by region

“ Through lobbying by the Stroke Foundation and stroke community, the Australian government awarded \$4 million dollars to fund the Paediatric Acute Code Stroke Study. WOW!! This research has the ability to change the lives of not only Australian children, but also children around the world with stroke. ”

Kylie Facer, mother of Anika who suffered a stroke shortly after birth and co-founder of support group Little Stroke Warriors



© Macedonian Stroke Association



90% of the SSOs have an organization website



58% of the SSOs have a Twitter account

**Website and Twitter**

90% (83/92) of SSOs reported having an organization website, and 58% (53/92) reported having a Twitter account.

- In Sub-Saharan Africa/Middle East/East Mediterranean, 73% (16/22) of SSOs reported having an organization website and 68% (15/22) reported having a Twitter account.
- In the Americas,, 95% (18/19) of SSOs reported having an organization website and 58% (11/19) reported having a Twitter account.
- In Europe, 97% (36/37) of SSOs reported having an organization website and 57% (21/37) reported having a Twitter account.
- In Asia/Oceania, 93% (13/14) of SSOs reported having an organization website and 43% (6/14) reported having a Twitter account.



Fig 20. SSOs with websites and Twitter accounts by region

An online presence via an organization website is very common with SSOs across all regions. Even in Sub-Saharan Africa/Middle East/East Mediterranean, where the frequency is lowest, nearly three-quarters (73%, 16/22) of SSOs reported having a website. Additionally, this region has a greater percentage of SSOs using Twitter than in all other regions. Overall, this snapshot of digital presence indicates that though the popularity of virtual platforms varies regionally, all of the SSOs in this report, regardless of region, are reaching beyond their borders virtually.

# SSO international and continental linkages 2018



Fig 21. SSO linkages 2018

\*\* SSOs in bold reported being a member of at least two international organizations in 2018

# Chapter 2

## The contribution of SSOs to the stroke care pathway

The WSO Global Stroke Guidelines and Action Plan includes a framework for stroke services that describes the continuum of stroke care from stroke onset to community reintegration and recovery. This framework has informed the mapping of SSO stroke awareness and prevention activities, treatment and rehabilitation support, and recovery activities. The questionnaire asked SSOs to identify:

- Their condition(s) of focus and the location of their service delivery
- Activities in 2018 they see as the most successful and why

The questionnaire also asked whether SSOs:

- Deliver palliative care
- Are involved in stroke research

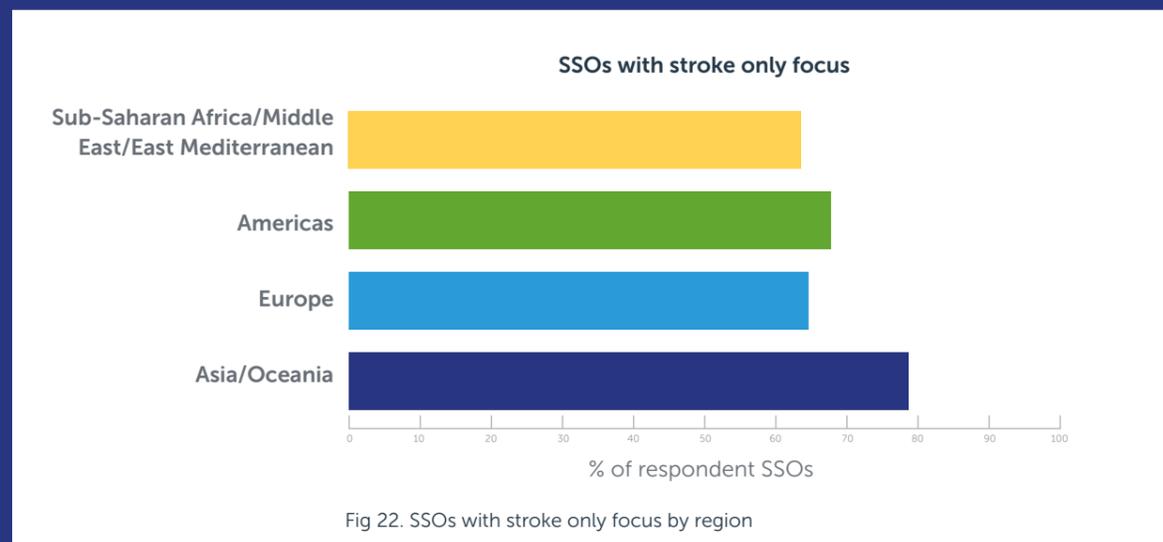
### A. Organization focus

#### Condition

Over two thirds (67%, 62/92) of SSOs reported that they focus on stroke only, with one organization specifically focused on perinatal and childhood stroke. This emphasis on stroke only is seen in all regions:

- Sub-Saharan Africa/Middle East/East Mediterranean: 64% (14/22)
- Americas: 68% (13/19)
- Europe: 65% (24/37)
- Asia/Oceania: 79% (11/14)

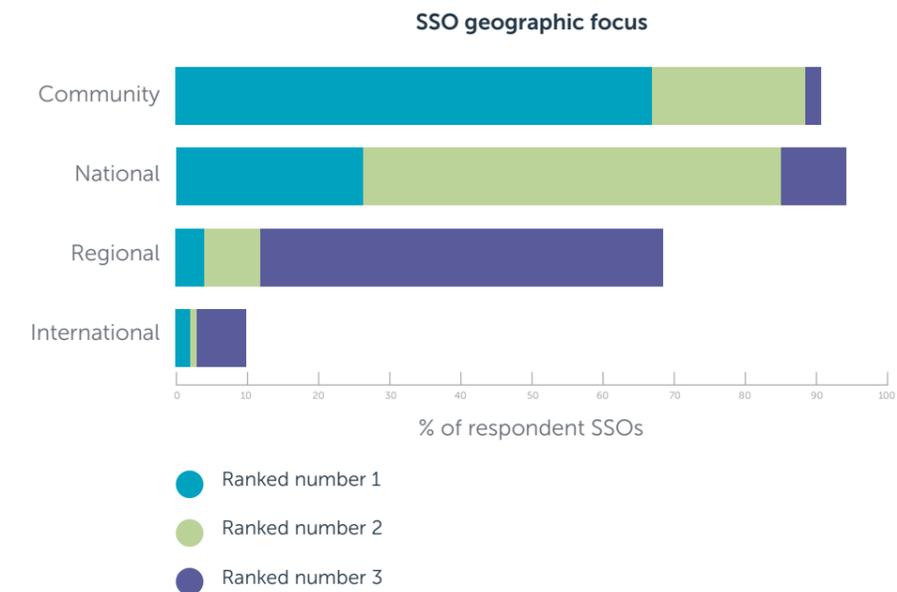
The remaining third of SSOs reported focusing on cardiovascular disease; stroke and another condition (hypertension, diabetes, heart disease, epilepsy, HIV/AIDs and associated NCDs); brain injury or disability.



#### Geography

SSOs target their activities to beneficiaries at different levels: community (individual, clinic, hospital); province or state; national; regional (sub continental and continental) and international. When asked to rank in order the levels at which they work, over two thirds (67%, 60/90) of respondent SSOs reported that the majority of their activities take place at the community level (i.e. ranked as number one).

- Community level - 67% (60/90) of respondent SSOs ranked this level as number 1, 21% (19/90) ranked it as number 2, 2% (2/90) ranked it as number 3
- National level - 26% (23/90) of respondent SSOs ranked this level as number 1, 59% (53/90) ranked it as number 2, 9% (8/90) ranked it as number 3
- Regional level (sub continental/continental) – 4% (4/90) of respondent SSOs ranked this level as number 1, 8% (7/90) ranked it as number 2, 57% (51/90) ranked it as number 3
- International level - 2% (2/90) of respondent SSOs ranked this level as number 1, 1% (1/90) ranked it as number 2, 7% (6/90)



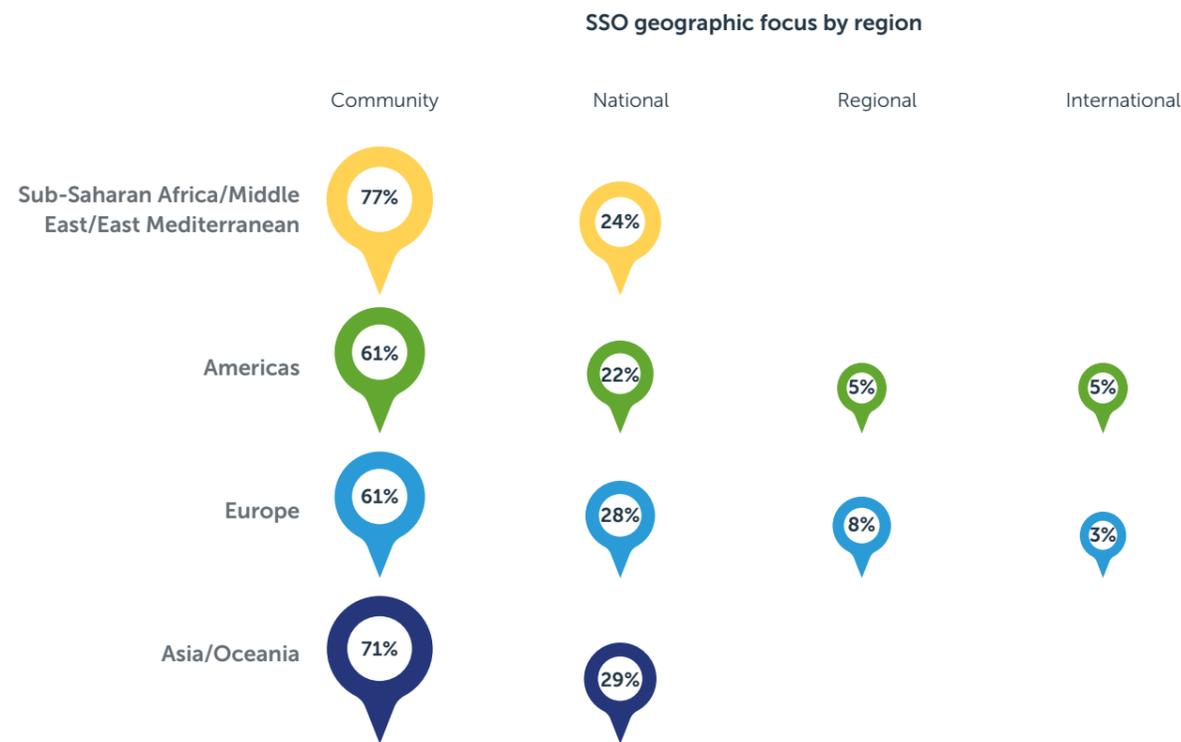


Fig 24. SSOs geographic focus by region

- In Sub-Saharan Africa/Middle East/East Mediterranean, over three quarters of SSOs (77%, 17/22) reported that the majority of their activities occur at the community level (i.e. ranked number one), and the remaining 23% (5/22) reported that the majority of their activities occur at the national level.
- In the Americas, 61% (11/18) of respondent SSOs reported that the majority of their activities occur at the community level (i.e. ranked number one). 22% (4/18) reported that the majority of their activities occur at the national level, and the remaining three reported that the majority of their activities occur at the state, regional and international level respectively.
- In Europe, 61% (22/36) of respondent SSOs reported that the majority of their activities occur at the community level (i.e. ranked number one). 28% (10/36) reported that the majority of their activities occur at the national level, 8% (3/36) at the regional level, and 3% (1/36) at the international level.
- In Asia/Oceania, 71% (10/14) of SSOs reported that the majority of their activities occur at the community level (i.e. ranked number one), and the remaining 29% (4/14) reported that the majority of their activities occur at the national level.

### INSIGHT

The relationship between the ability of SSOs to deliver the majority of their activities at the state, national, regional, or international level, and their access to government funding varies across regions.

In Sub-Saharan Africa/Middle East/East Mediterranean, none of the five SSOs delivering the majority of their activities at national level receive government funding. These five SSOs receive funding from founder and public donations, membership fees, support from a host organization and selling of merchandise.

In the Americas, 43% (3/7) of the SSOs that deliver the majority of their activities beyond the community level (i.e. at the state, national, regional, or international level) have access to government funding.

The pattern is the same in Europe, where 43% (6/14) of SSOs that deliver the majority of their activities beyond the community level have access to government funding.

Among the SSOs that deliver the majority of their activities at the national level in Asia/Oceania, there is an even split between those that have government funding (2/4) and those that do not (2/4).

## B. Activities across the stroke care pathway

### Awareness and prevention

81% (72/89) of respondent SSOs reported that they promote FAST (i.e. signs of stroke) and 91% (81/89) reported that they provide local and national public education on risk factors. These two activities appear in the top three most frequently reported awareness and prevention activities by respondent SSOs in all regions.

56% (50/89) of respondent SSOs reported that they provide secondary prevention information and advice. This activity is among the top three most frequently reported awareness and prevention activities in all regions except Sub-Saharan Africa/Middle East/East Mediterranean.

44% (39/89) of respondent SSOs reported that they deliver health screening events, however this appears in the top three most frequently reported awareness and prevention activities in the Sub-Saharan Africa/Middle East/East Mediterranean region only.

The top three most frequently reported awareness and prevention activities in each region are:

#### Sub-Saharan Africa/Middle East/East Mediterranean

- Local and national public education on risk factors - 95% (21/22)
- Promotion of FAST - 73% (16/22)
- Health Screening Events - 73% (16/22)

#### Americas

- Local and national public education on risk factors - 89% (16/18)
- Promotion of FAST - 83% (15/18)
- Secondary prevention education and support - 72% (13/18)

#### Europe

- Local and national public education on risk factors - 89% (31/35)
- Promotion of FAST - 89% (31/35)
- Secondary prevention education and support - 54% (19/35)

#### Asia/Oceania

- Local and national public education on risk factors - 100% (14/14)
- FAST promotion - 71% (10/14)
- Secondary prevention education and support - 64% (9/14)

### INSIGHT

#### Awareness and Prevention

The frequency of health screening events is the highest of all regions in Sub-Saharan Africa/Middle East/East Mediterranean.

The frequency of secondary prevention education and support is the highest of all regions in the Americas.

The frequency of promotion of FAST is the highest of all regions in Europe.

The frequency of local and national public education on risk factors is highest of all regions in Asia/Oceania.

The reasons for this frequency of reporting in specific regions is beyond the scope of this report but is an area for further research.

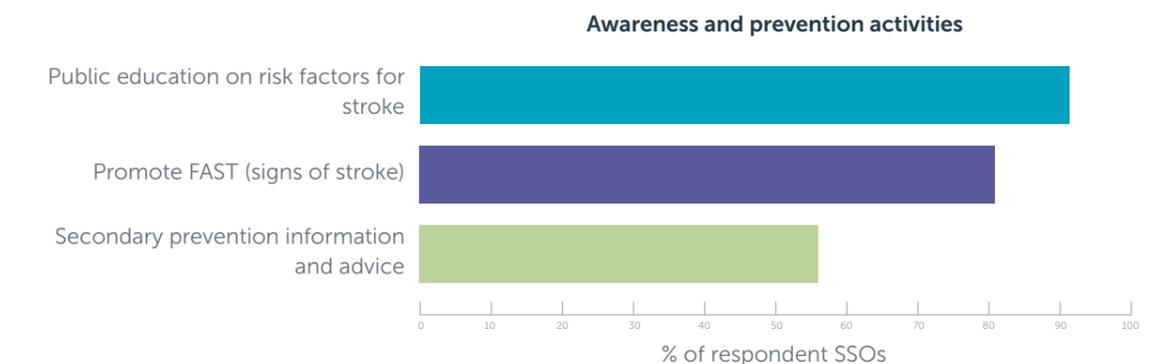


Fig 25. Most frequently reported awareness and prevention activities

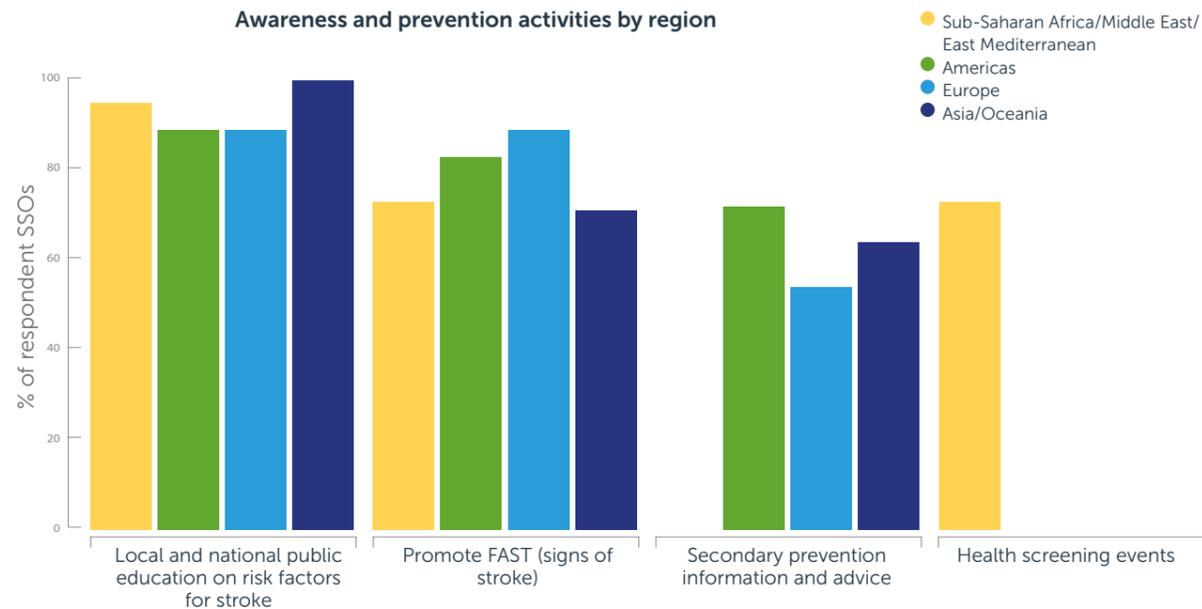


Fig 26. Most frequently reported awareness and prevention activities by region

## Treatment and Rehabilitation Support

83% (75/90) of respondent SSOs reported that they provide patient, family and carer advice and 80% (72/90) reported that they provide information materials. These two activities appear in the top three most frequently reported activities in support of treatment and rehabilitation by SSOs in all regions.

51% (46/90) of respondent SSOs reported that they provide rehabilitation activities. This activity is among the top three most frequently reported treatment and rehabilitation support activities in Sub-Saharan Africa/Middle East/East Mediterranean (73%, 16/22) and Asia/Oceania (64%, 9/14).

51% (46/90) of respondent SSOs reported that they engage in patient and policy advocacy. This activity is among the top three most frequently reported treatment and rehabilitation support activities in the Americas (44%, 8/18) and Europe (56%, 20/36).

If we look at Oceania (Australia, New Zealand and Fiji) separately from Asia, patient and policy advocacy is among the top three treatment and rehabilitation support activities, with 75% (3/4) of SSOs in Oceania engaging in this activity.

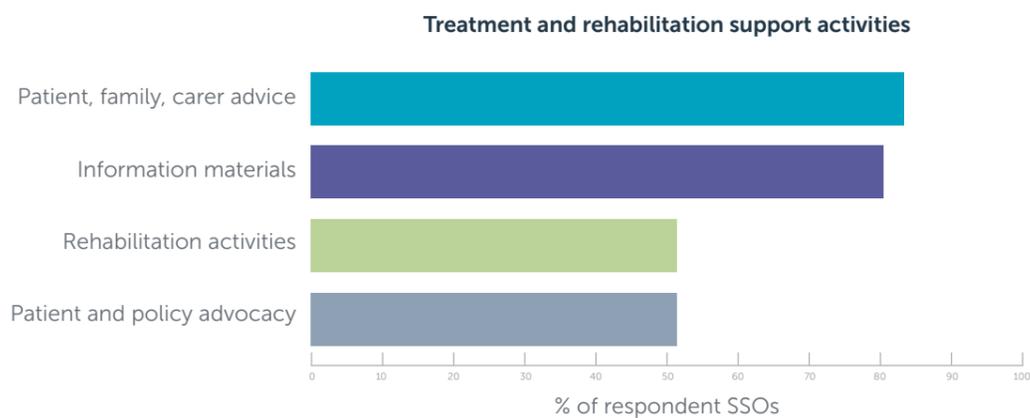


Fig 27. Most frequently reported treatment and rehabilitation support activities

The top three most frequently reported treatment and rehabilitation support activities in each region are:

### Sub-Saharan Africa/Middle East/East Mediterranean

- Information materials – 68% (15/22)
- Patient, family, carer advice – 82% (18/22)
- Rehabilitation activities – 73% (16/22)

### Americas

- Information materials – 72% (13/18)
- Patient, family, carer advice – 89% (16/18)
- Patient and policy advocacy – 44% (8/18)

### Europe

- Information materials – 94% (34/36)
- Patient, family, carer advice – 81% (29/36)
- Patient and policy advocacy – 56% (20/36)

### Asia/Oceania

- Information materials – 71% (10/14)
- Patient, family, carer advice – 86% (12/14)
- Rehabilitation activities – 64% (9/14)

**INSIGHT**

**Treatment and Rehabilitation Support**

The frequency of rehabilitation activities is the highest of all regions in Sub-Saharan Africa/Middle East/East Mediterranean.

The frequency of patient, family and carer advice activities is the highest of all regions in the Americas.

The frequency of production and dissemination of information materials is highest of all regions in Europe.

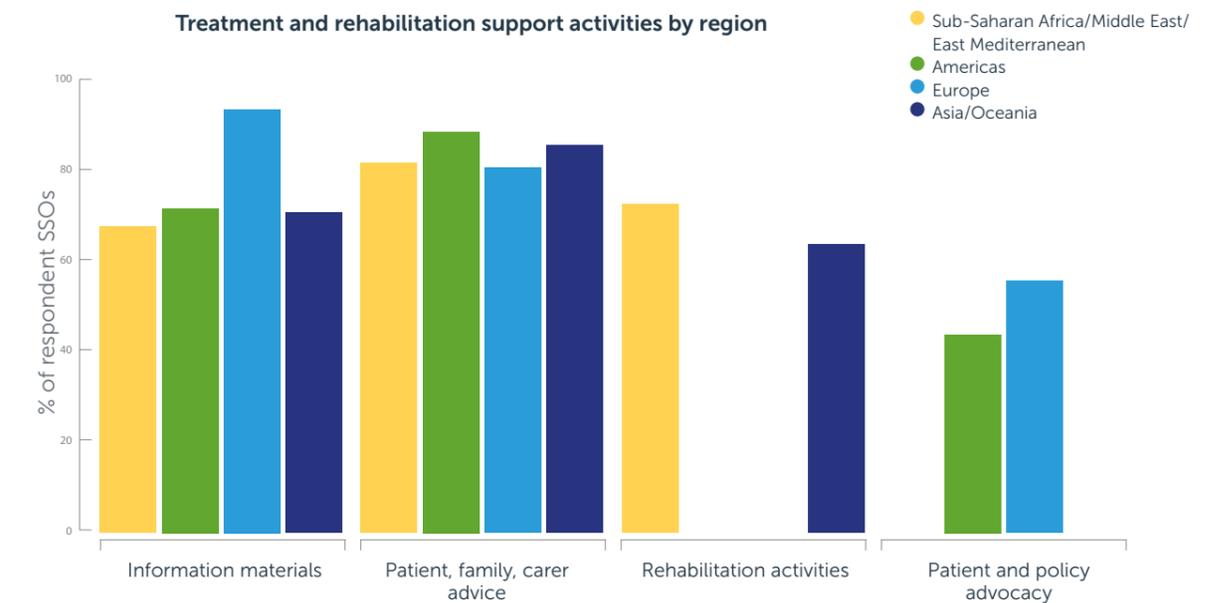


Fig 28. Most frequently reported treatment and rehabilitation support activities by region

## Recovery

77% (69/90) of respondent SSOs reported facilitating support groups, while 70% (63/90) reported providing information materials. These two activities are among the most frequently reported recovery activities by SSOs in all regions

40% (36/90) of respondent SSOs engage in recovery-focused patient and policy advocacy. This is among the top three most frequently reported recovery activities in all regions except Asia/Oceania. However, if we look at Oceania (Australia, New Zealand and Fiji) separately from Asia, 75% (3/4) report engaging in recovery-focused patient and policy advocacy.

The top three most frequently reported recovery activities in each region are:

### Sub-Saharan Africa/Middle East/East Mediterranean

- Information materials - 45% (10/22)
- Support groups – 86% (19/22)
- Patient and policy advocacy – 36% (8/22)

### Americas

- Information materials – 78% (14/18)
- Support groups – 56% (10/18)
- Patient and policy advocacy - 50% (9/18)

### Europe

- Information materials – 78% (28/36)
- Support groups – 81% (29/36)
- Patient and policy advocacy – 44% (16/36)

### Asia/Oceania

- Information materials – 79% (11/14)
- Support groups – 86% (12/14)
- Home visits – 36% (5/14)

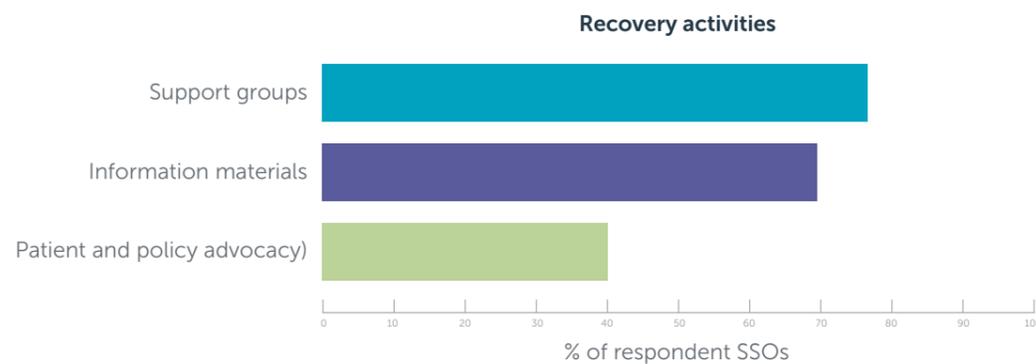


Fig 29. Most frequently reported recovery activities

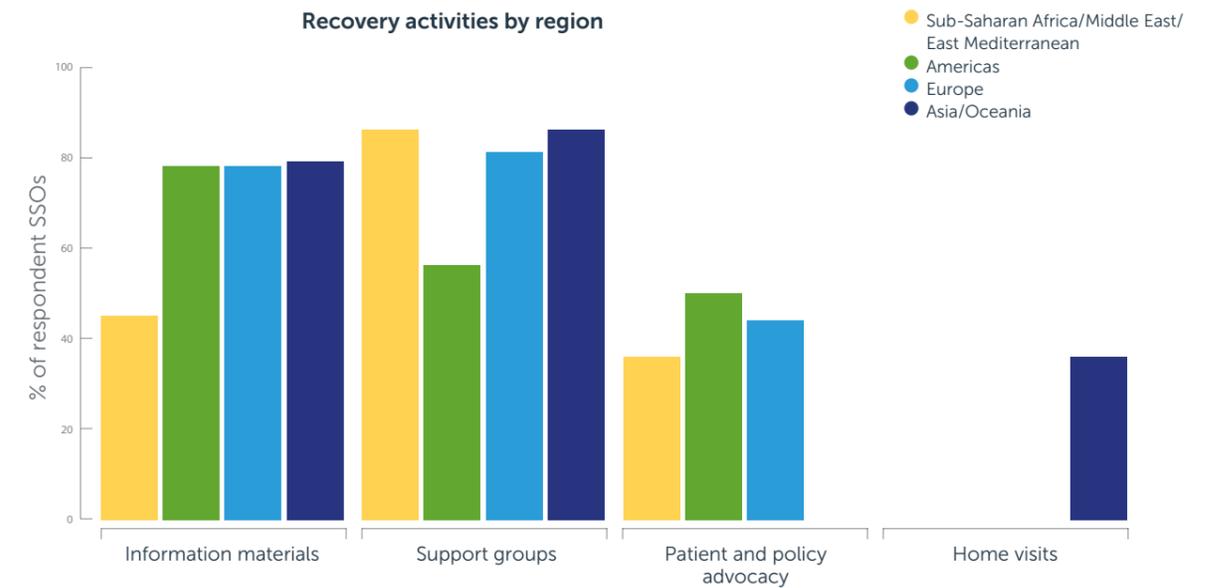


Fig 30. Most frequently reported recovery activities by region



## INSIGHT

### Recovery

The frequency of support groups as a recovery activity is the highest in both Sub-Saharan Africa/Middle East/East Mediterranean and Asia/Oceania.

The frequency of patient and policy advocacy activities is the highest of all regions in the Americas.

The frequency of production and dissemination of information materials and home visits is highest of all regions in Asia/Oceania.

## Palliative care

Overall, there is low engagement of SSOs (10%, 9/90) in the provision of palliative care in all regions. Sub-Saharan Africa/Middle East/East Mediterranean has the highest number of SSOs reporting involvement in palliative care, but this is still only just under a quarter (23%, 5/22). No SSOs in Asia/Oceania reported providing palliative care services.



**10%** of SSOs provide palliative care

## C. Participation in research

60% (54/90) of respondent SSOs reported that they participate in research. Participation in research activities includes collaboration, funding, dissemination and patient involvement.



60% of respondent SSOs participate in research

### Heart and Stroke Foundation Canada



Since 1952, Heart and Stroke has invested more than \$1.55 billion CAD in vital heart and brain research. Heart and Stroke funds investigator-driven research, builds the capacity and strengths of Canada's research community and invests in priorities that will have the greatest impact and benefit to people living with or at risk of heart conditions, stroke or related dementia. In 2018 Heart and Stroke invested \$33.2 million CAD in life-saving research.

- Since launching the Women's Heart and Brain Health initiative in 2016, Heart and Stroke has funded 15 researchers from 11 institutions in five provinces, with an initial \$5 million CAD investment from the 2016 Canadian Federal budget along with philanthropic support. In 2018, Heart and Stroke leveraged an additional \$3.5 million CAD through partnerships with Canadian Institutes of Health Research (CIHR), Institute of Indigenous Peoples Health, Institute of Circulatory and Respiratory Health, Institute of Gender and Health and New Brunswick Health Research Foundation. This supported the award for four chairs in women's heart and brain health in 2018.
- Heart and Stroke supported 750 researchers in medical institutes, universities, hospitals and communities across Canada in 2018.

<https://www.heartandstroke.ca/what-we-do/research>

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### Stroke Association UK



The Stroke Association sees research as a vital part of its work and has funded over £55 million of stroke research since the early 1990s. Stroke Association funded research has covered all areas related to stroke care and support, from prevention and emergency care to rehabilitation and long-term support. The Stroke Association has a Patient and Public Involvement group, Stroke Voices in Research, that brings the perspectives and experience of people with lived experience of stroke to shape the organization's research activities.

In 2018–19, the Stroke Association:

- Invested £1.1 million in new research into stroke rehabilitation and long-term support to help people affected by stroke to make the best possible recovery.
- Invested £800,000 in capacity building awards, supporting researchers to become the stroke research leaders of the future. All four fellowships focus on rehabilitation.
- Supported a Reader Award, which is looking at treatment to improve recovery after stroke.

<https://www.stroke.org.uk/research>

### Stroke Foundation Australia



The Stroke Foundation supports stroke research in three different ways:

- Funding annual research grants to promote stroke research capacity and generate new stroke knowledge
- Building strong partnerships to improve stroke research outcomes
- Leveraging all Stroke Foundation activities to deliver better outcomes for stroke care through research. This includes the consideration of work done in program planning and evaluation, better use of the extensive data held by the Stroke Foundation, and a focus on research priority areas.

<https://strokefoundation.org.au/en/What-we-do/Research>

In 2018, Stroke Foundation's research program awarded 6 Research Grants, including 4 Seed Grants and two new Memorial grants centred on stroke in young people, generously established by families in memory of their sons' deaths following stroke.

<https://strokefoundation.org.au/What-we-do/Research/Research-grants/2019-grant-recipients>

Further to this, Stroke Foundation secured a partnership with The Australian Government through the Medical Research Future Fund (MRFF) to deliver a 'Return to life, return to work' research package including clinical trials to enhance stroke recovery.

In addition, Stroke Foundation furthered its own research work. For 20 years the Stroke Foundation has conducted an annual National Stroke Audit – alternating between Acute Stroke Services and Rehabilitation Services. Audit reports are produced at a hospital, regional and national level to drive quality improvement activity and inform health policy e.g., establishment of new stroke units. Stroke Foundation and Cochrane Australia also commenced the world's first 'Living' Stroke Clinical Guidelines Pilot, also funded by a grant from the Medical Research Future Fund. This project will revolutionise the rapid translation of medical discoveries into clinical practice, saving lives and improving health outcomes for future generations.

In 2018 the organization also supported 36 research projects seeking participants by promoting their study through our channels.

### North Macedonia Association for the fight against Stroke



The Association for the fight against Stroke is a partner in the project 'Improving Quality and Accessibility of Health Care and Social services Centres in Cross-Border Regions' which is funded by the European Union INTERREG IPA Cross Border Cooperation Programme. The Quality Health project commenced in April 2018 and the overall objective is the improvement of the level of Health and Social Care system in the public sector for people in the cross border area.

This is an important collaboration for the Association, which is the first association of its kind in the country, and is an opportunity to improve stroke prevention measures and meet the needs of people affected by stroke through the health and social care system.

The expected main outputs of the project include collection and analysis of the data from questionnaires to learn more about stroke risk factor prevalence in the southwestern region of North Macedonia, and about the effectiveness of health education methods.

## Brazilian Stroke Network

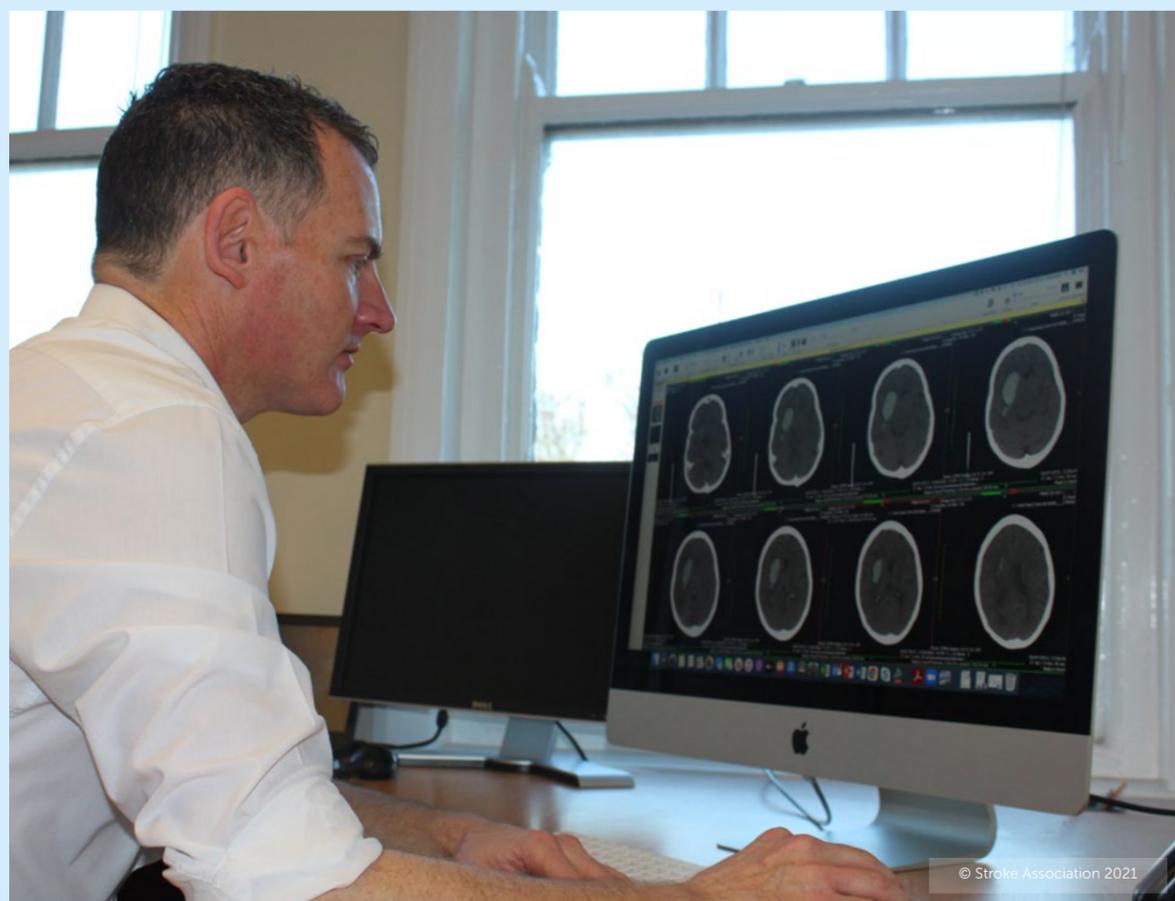
The Brazilian Stroke Network is a NGO created with the purpose of improving education, assistance and research in stroke in Brazil. It was founded in 2008 and since then has been working with the Ministry of Health to develop and to implement the National Stroke Plan.

The Brazilian Stroke Network's first step was research to evaluate the situation of stroke care in the country and to assess the population's knowledge about stroke.

In 2013, sponsored by the Ministry of Health, the Brazilian Stroke Network started a randomized clinical trial in acute care to support the implementation of thrombectomy in the country.

The Network will begin a clinical trial in primary care for primary prevention of stroke and cognitive decline in 2021. This is part of the WSO's initiative Cut Stroke in Half, and is sponsored by Hospital Moinhos de Vento and the Ministry of Health. The goal is to support the reorganization of primary care in Brazil using evidence based strategies for lifestyle modification and the treatment of hypertension.

The Brazilian Stroke Network also participates in international academic research in partnership with other international networks including the Global Alliance of Independent Networks Focused on Stroke Trials(GAINS).



“It's so great to meet like-minded people. For my sanity it was so necessary to talk to other people. Life after stroke is so lonely, you feel isolated... Croí is a place to come and feel relaxed, and where no one will judge you”  
Mary Kelly, wife of John Kelly, who is a stroke survivor, Ireland

## D. Stories of success

The SSO Global Mapping has shown that SSOs are delivering activities across the stroke care pathway and that this is happening across all four regions. 88% (79/90) of respondent SSOs shared at least one example of an activity in 2018 that they deemed successful in improving stroke awareness, treatment, and care. Below is a selection of examples, which demonstrate the outcomes achieved by SSOs across the world, in different contexts and with varying resources.

### Awareness and prevention

#### Stroke Foundation Australia



##### Activity: Political Advocacy

In the Stroke Foundation's non-partisan political advocacy strategy, a multi-pronged approach is used to disseminate key messages to candidates running for election and other interested parties. Stroke Foundation provides community members with an advocacy toolkit, which helps facilitate engagement with their local candidates using a variety of channels. This approach helps normalise the advocacy process within the stroke community, providing a platform from which they are able to advocate strongly for change.

In 2018, this strategy achieved success, with Stroke Foundation securing funding commitments from major political parties in two of the three Australian state elections, for key programs: a community education campaign to increase awareness of the F.A.S.T. message, a 'Community of Practice' to improve care, and a patient follow-up service.



© Stroke Foundation Australia

#### Associação Brasil AVC



##### Activity: World Stroke Day Event 2018

Associação Brasil AVC organized its third Race and Walk against stroke in Joinville, Brazil with 1,500 joining the race and side events. The overall goal of the event was to encourage the public to get involved in physical activity and to access information on healthy lifestyles, and primary and secondary prevention. Alongside the race and walk there were also side events including health promotion and health booths hosted by a range of different organisations including colleges, rehabilitation services, emergency services, and clinics.

The event was a success as it attracted a large number of people, there was collaboration between a range of different stakeholders, including medical professionals, allied health, and non-profit organisations. The event was also inclusive, ensuring tailored messages, materials and activities for younger and older people. Children were able to join the event and there was a dedicated 'Kids Space', along with dance and music performances.

#### National Network Heart for Heart Foundation Bulgaria



##### Activity: Stroke Prevention Programme

The National Network Heart for Heart Foundation named the initiative 'What is your reason for preventing a stroke?'

The aim of the campaign was to raise awareness of preventing and controlling stroke risk factors by reaching people in their workplace.

The Foundation was able to mobilize volunteers to deliver the programme within two months to two of the largest tailoring companies in the country, and in 12 kindergartens and schools. The staff in these workplaces accessed free medical examinations and information materials.

The initiative was a success because nearly 1,000 people accessed the health screening programme; 600 at the tailoring companies and 352 in the kindergartens and schools. Working in collaboration with the workplaces meant that the programme was easily accessible to the employees and was a benefit of their employment. It also meant that the employers could continue to promote the health messages in the workplace.

#### Heart and Stroke Foundation Canada



##### Activity: 2018 Annual Stroke Report

The annual Stroke Report from Heart and Stroke shines a spotlight on a critical issue affecting the future of stroke health in Canada: The [2018 Stroke Report](#), Lives Disrupted.

Women are disproportionately affected by stroke throughout their lives. The Heart and Stroke [2018 Stroke Report](#) looks at the challenges they face across the health system, and profiles survivors.

Lives Disrupted, along with the [2018 Heart Report](#) Ms Understood, raised awareness of the health inequities facing women through a combined total of almost 150 million impressions (online and in the media).

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## Treatment and rehabilitation support

### Dr. Bindu Menon Foundation, India

#### Activity: Neurology on Wheels Programme

The Neurology on Wheels programme is a community outreach programme to resource poor villages in Nellore, Andhra Pradesh. In 2018, in Nellore district there were 11 neurologists for a population of 600,000, translating to one neurologist for 50,000 people.

The motto for the Neurology on Wheels programme is 'We Reach, We Teach, We Treat.' The programme team visits villages and liaises with the village head and community health workers to plan the activities. The activities begin with an awareness programme followed by a free medical camp with health screening and free distribution of medicine.

The mobile programme is providing access to stroke awareness and primary and secondary prevention in areas with limited access to medical services. To date, the Foundation has reached 29 villages. Over 10,000 people have attended education sessions, 294 new cases of hypertension have been identified and more than 111 stroke survivors have been able to access medical treatment.



### Japan Stroke Association

#### Activity: Collaborative Advocacy and the Japan Basic Act on CVDs

Since 2009, the Japan Stroke Association has been advocating for improved stroke policy in Japan. Its initial proposal for a Stroke Control Act was scrapped due to changes in the legislature and there was also resistance from some law makers to a single disease-focused law. The Japan Stroke Association then joined with a number of other condition-focused organisations along with concerned citizens, patient groups, family members, and academic and professional societies. They developed a new strategy resulting in the broader Stroke and Cardiovascular Disease Control Act. After repeated petitions to legislatures and numerous public rallies, in December 2018 the Act passed.

The next step is to develop the Basic Plan to Promote Stroke and Cardiovascular Disease Control Programmes. This plan includes: public awareness of stroke prevention and emergency response; improvements of local emergency transport, local medical facilities, quality of life of patients and coordination and skills development of relevant professionals.

Following the development of the Basic Plan, each prefecture shall make a Prefectural Plan to Promote the Stroke and Cardiovascular Disease Control Program.



### National Stroke Association of Malaysia

#### Activity: Daily Rehabilitation Activities

The National Stroke Association of Malaysia (NASAM) has nine centres across the country. Daily rehabilitation activities are delivered at the centres with an average of 400 to 500 members participating each day.

NASAM's team of professional therapists make it a priority to ensure that the recovery journey of a stroke survivor is aimed at restoring self-esteem and dignity. NASAM looks to the physical, emotional and social needs of stroke survivors, and its integrated approach includes physiotherapy, speech therapy, occupational therapy, psychosocial support and recreational activities as well as various complementary therapies.

NASAM seeks to inspire and motivate stroke survivors to reach and achieve their goals. As part of this mission, NASAM has held Stroke Games (in 2017 and 2019). Preparation for the Games becomes a part of the activities at the centres, which organize their own teams for the event.

The Games proved to stroke survivors and the general public that with rehabilitation, stroke survivors can compete, run, play games and have a fulfilling life after a stroke.



### Croí - The West of Ireland Cardiac and Stroke Foundation

#### Activity: Stroke Communications Group

Croí offers a range of stroke support services, including education, carer support, risk factor management, survivor empowerment, and communications rehabilitation. The Croí Health Team link closely with clinicians and stroke teams in regional hospitals and patient advocates in order to raise awareness about stroke and stroke prevention, run awareness campaigns and intervention programmes.

Communication sessions with a speech and language therapist have enabled stroke survivors with speech impairments to gain confidence with speaking. The group participates in new awareness and education initiatives, including lectures with students at the local university and training with restaurant staff on how to communicate with people with speech impairments.



## Stroke Foundation, Australia

### Activity: Clinical Guideline Development



Stroke Foundation has produced clinical guidelines for stroke since 2005. In 2018, the Stroke Foundation began the world's first Living Guidelines for Stroke Management Project in partnership with Cochrane Australia and supported by the Australian Government's Medical Research Future Fund.

This three-year pilot project utilises new technologies in machine learning, citizen science and peer review to ensure the latest in evidence based research is translated into clinical practice. The living guidelines use 'evidence surveillance' systems that continually scan for relevant new research, incorporate it into evidence summaries and rapidly update guideline recommendations whenever there is a substantial change in the evidence.

The ultimate goal is to create a near real-time, closed-loop evidence system in which global evidence and local data are integrated for insight and health decision making. This project will revolutionise the rapid translation of medical discoveries into clinical practice, saving lives and improving health outcomes for future generations.

<https://informme.org.au/Guidelines/Living-guidelines-for-stroke-management>

“ The Macedonian Stroke Association provides support to stroke survivors and their family caregivers as they try to rebuild their lives. We aim to ensure all stroke survivors regardless of their location and social and economic status access the stroke care that they need ”

Prof. Anita Arsovska, MD, PhD, Republic of North Macedonia

## Recovery

### Finnish Brain Association



#### Activity: Juttu-tupa Groups (communication cottages) for People with Aphasia.

Communication cottages are held in adult education centres across Finland. The aim of the groups is to enhance the possibilities for people with aphasia to participate in society, to access peer-support and to learn and try new communication activities.

The group facilitators, trained by the Finnish Brain Association, lead the groups in both Finnish and Swedish. The facilitators support participants as they engage in conversation about current topics of interest and the news. A range of materials including images, writing, and drawing are used to support communication. Participants can join the group with an interpreter or an assistant, and is entitled to a transport service.

In 2018 there were 35 aphasia groups running across Finland with 5-10 participants each, and a total of 250 participants.

### Red Bracelet Volunteer Corps, Chinese Stroke Association



#### Activity: Published Handbook for Stroke Patients and Caregivers

The 2017 Handbook for Stroke Patients and Caregivers is a collaboration between the Red Bracelet Corps and the Chinese Stroke Association. This is a significant activity for the Chinese Stroke Association as it is the first book published in China focusing on educating stroke survivors and their carers.

The handbook includes chapters on basic knowledge of stroke, stroke epidemiology, stroke signs and emergency response, diagnosis and treatment, nursing during hospitalization, nutrition management, rehabilitation after discharge, and measures to prevent a second stroke recurrence. The handbook also includes locally appropriate information, such as Tai Chi for healthy lifestyles.

The book is a vital resource for the national network of nearly 40,000 Red Bracelet volunteers in the public campaign and outreach work, and hundreds of copies of the book are distributed for free during these events.

### Stroke Aid Foundation Ghana



#### Activity: National Health Insurance Scheme (NHIS) Registration for Stroke Survivors

In Ghana, a major barrier for stroke survivors to access regular medical check-ups and rehabilitation is the financial cost. In order to respond to this barrier, Stroke Aid Foundation introduced the Operation 1,000 project in 2018. The goal of the project is to register at least 1,000 stroke survivors on the National Health Insurance Scheme (NHIS) through which they are entitled to support for medical and rehabilitation costs that are vital to support life after stroke.

Stroke Aid Foundation raised funds to support the project through a crowdsourcing initiative. Since 2018, 350 stroke survivors have been registered on the scheme, with 65% below 60 years of age. The stroke survivors on the scheme can now access regular medical check-ups and attend physiotherapy appointments at no cost. Of particular note is that the majority of survivors that have registered have seen improvements in their functional independence and some have returned to their previous work.

## Stroke Foundation New Zealand



### Activity: Return to Work Programme

Stroke Foundation New Zealand's Return to Work service provides expertise and support to guide stroke survivors through the process of returning to employment. This free service is available to stroke survivors under the age of 65. Many stroke survivors want to return to work as soon as possible to regain their independence, but it needs to be approached in the right way to avoid serious setbacks. A big part of the job is education; understanding aspects of strokes and stroke recovery people may not be aware of. It is also about educating employers who may not have had experience in working with employees who are recovering from a stroke.

In the financial year 2018-19, 211 stroke survivors engaged with the Return to Work programme, with 111 new clients being referred. Over 56% of those that joined the programme were able to return to work. Not only does the Return to Work service make an important difference to the lives of stroke survivors and their families, Stroke Foundation New Zealand estimates that the results they have achieved to date will save more than \$22M in benefit payments.

<https://www.stroke.org.nz/annual-report>

## Stroke Action Nigeria



### Activity: Stroke Ambassadors Development Programme

Stroke Action Nigeria is a national stroke support organization with the mission to provide services that help to reduce the incidence, complications and burden of stroke. Volunteers are the backbone of the work of Stroke Action. The organization recruits stroke survivors, carers, lay people, and health workers as volunteers.

The volunteers participate in the Volunteer Stroke Ambassador's Development Programme, which increases stroke awareness and includes information and education on roles and responsibilities, and the skills and competencies needed for engaging in stroke awareness and support. Volunteer roles include administrators, befrienders, campaigners, fundraisers, outreach workers, and Life After Stroke Centre support staff such as activity coordinators and peer coaches.

In 2018, Stroke Action had 106 Volunteer Stroke Ambassadors operating across 10 of 37 states.

Stroke survivors who take up the role of Volunteer Stroke Ambassador and wish to return to work can also choose to join Stroke Action's Stroke Survivor Entrepreneur Programme, which can lead to paid employment with Stroke Action.

# Chapter 3 Enhancing the role of SSOs

## A. Challenges

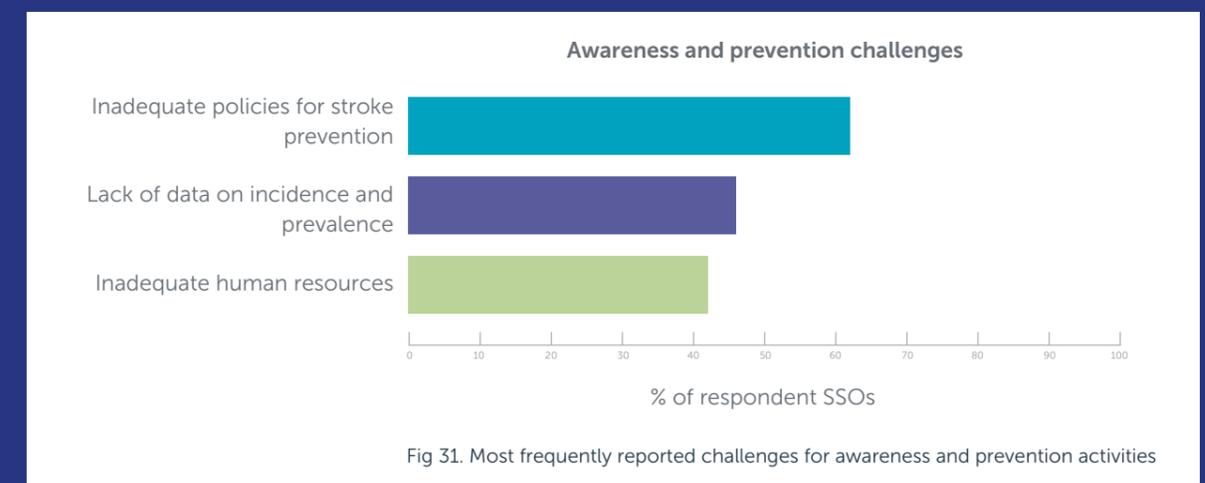
The SSOs were asked to rank the top challenges they face in delivering activities at each stage of the stroke care pathway.

### Awareness and prevention

The challenges most frequently reported by all respondent SSOs to delivering awareness and prevention activities are:

- Inadequate policies for stroke prevention - 62% (56/90)
- Lack of data on incidence and prevalence - 46% (41/90)
- Inadequate human resources - 42% (38/90)

Examining the data by region, there is some variability in the challenges reported. Though the three challenges listed above mirror those ranked and reported by the Sub-Saharan Africa/Middle East/East Mediterranean and Europe regions, in the Americas, 44% (8/18) of respondent SSOs reported 'no national health promotion initiatives', as a challenge, and in Asia/Oceania 50% (7/14) of respondent SSOs reported 'low health literacy' as a challenge. All four regions reported the inadequate stroke prevention policy environment to be a substantial challenge to stroke awareness and prevention.



Breaking it down by region, the challenges most frequently reported by respondent SSOs to delivering awareness and prevention activities are:

**Sub-Saharan Africa/Middle East/East Mediterranean**

- Lack of data on incidence and prevalence – 68% (15/22)
- Inadequate policies for stroke prevention – 59% (13/22)
- Inadequate human resources – 59% (13/22)

**Americas**

- Inadequate policies for stroke prevention – 67% (12/18)
- No national health promotion initiatives – 44% (8/18)
- Lack of data on incidence and prevalence – 39% (7/18) and stigma and discrimination – 39% (7/18)

**Europe**

- Inadequate policies for stroke prevention – 56% (20/36)
- Lack of data on incidence and prevalence - 44% (16/36)
- Inadequate human resources – 44% (16/36)

**Asia/Oceania**

- Inadequate policies for stroke prevention – 79% (11/14)
- Low health literacy – 50% (7/14)
- Inadequate human resource – 43% (6/14)

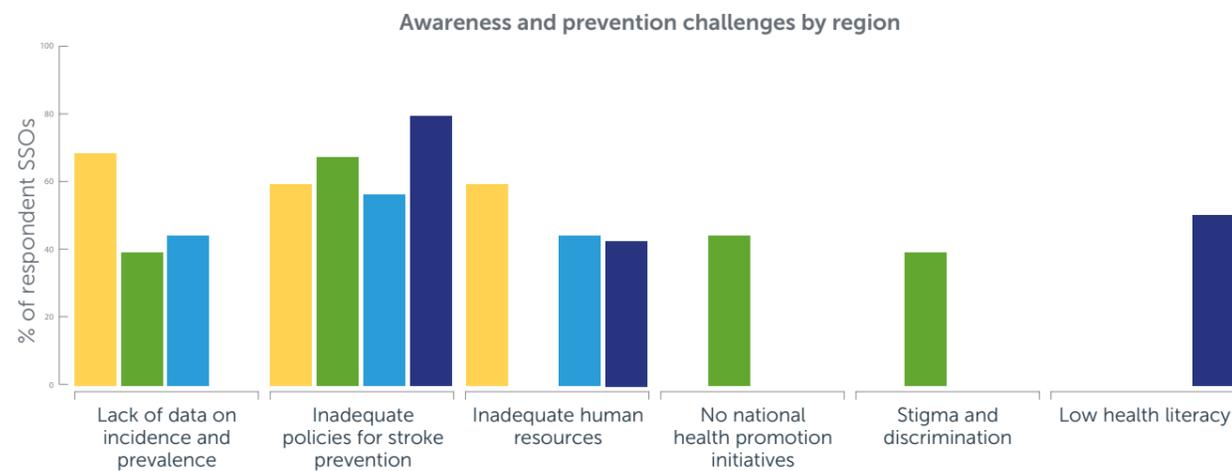


Fig 32. Most frequently reported challenges for awareness and prevention activities by region

**Treatment and rehabilitation support**

The challenges most frequently reported by all respondent SSOs to delivering treatment and rehabilitation support activities are:

- Inadequate strategies for stroke treatment and rehabilitation (in operating context) – 78% (69/88)
- Low awareness of stroke symptoms and emergency response (in the general population) - 56% (49/88)
- Inadequate recognition of rehabilitation (in the operating context) – 35% (31/88)

Again, there is some variability in the regions. These three challenges were also the top three reported in the Americas and Asia/Oceania, however in Sub-Saharan Africa/Middle East/East Mediterranean 50% (11/22) of SSOs reported 'no stroke units' as one of the top three challenges. Additionally, in Europe 41% (14/34) of respondent SSOs reported 'inadequate human resource' as one of the top three challenges. With it being a shared challenge across all regions, and with nearly 80% of all respondent SSOs identifying it as one, inadequate strategies for stroke treatment and rehabilitation are a substantial barrier.

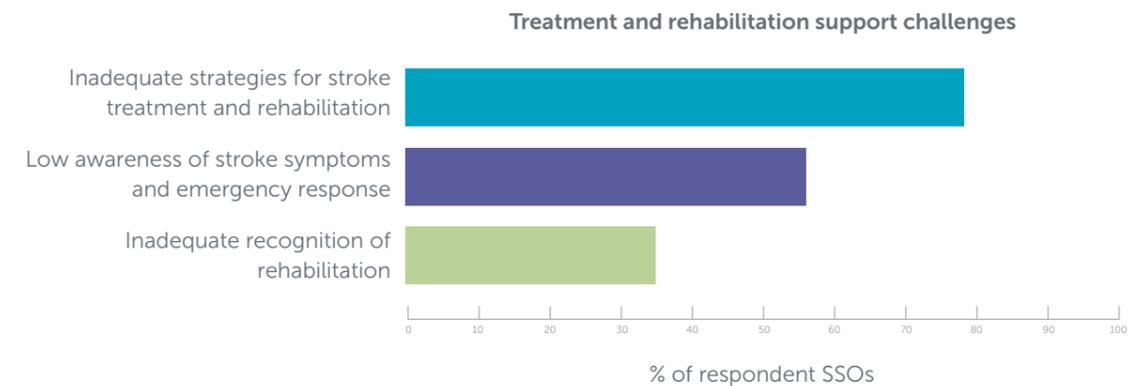


Fig 33. Most frequently reported challenges for treatment and rehabilitation activities

Again, breaking it down by region, the challenges most frequently reported by respondent SSOs to delivering treatment and rehabilitation support are:

**Sub-Saharan Africa/Middle East/East Mediterranean**

- Inadequate strategies for stroke treatment and rehabilitation – 73% (16/22)
- Low awareness of stroke symptoms and emergency response – 68% (15/22)
- No stroke units – 50% (11/22)

**Americas**

- Low awareness of stroke symptoms and emergency response – 72% (13/18)
- Inadequate strategies for stroke treatment and rehabilitation – 67% (12/18)
- Inadequate recognition of rehabilitation – 50% (9/18)

**Europe**

- Inadequate strategies for stroke treatment and rehabilitation – 62% (21/34)
- Inadequate recognition of rehabilitation – 44% (15/34)
- Inadequate human resources – 41% (14/34)

**Asia/Oceania**

- Low awareness of stroke symptoms and emergency response – 79% (11/14)
- Inadequate recognition of rehabilitation – 64% (9/14)
- Inadequate strategies for stroke treatment and rehabilitation – 50% (7/14)

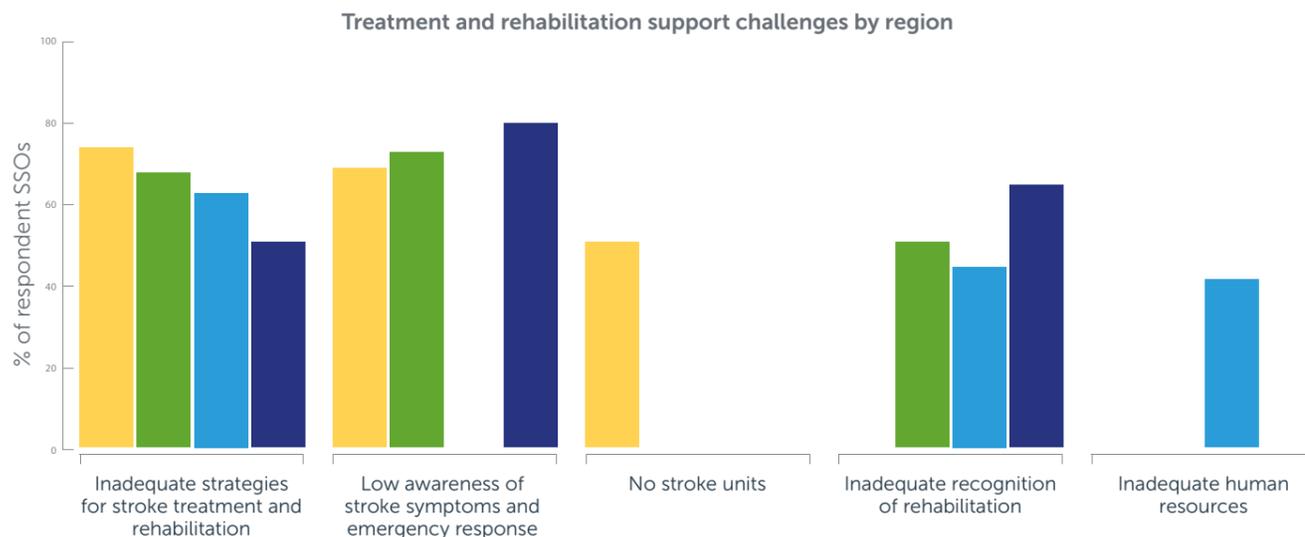


Fig 34. Most frequently reported challenges for treatment and rehabilitation activities by region

**Recovery**

The challenges most frequently reported by all respondent SSOs to delivering recovery activities are:

- Limited support services (in the community) – 84% (74/88)
- Inadequate policies to support recovery (in the operating context) – 70% (62/88)
- Insufficient funds (of the organization) – 80% (70/88)

Interestingly, these three challenges were also the same top three reported challenges to delivering recovery activities in each of the regions. This indicates the significance that the availability of services, the policy environment, and funding have to SSOs and their ability to deliver recovery activities.

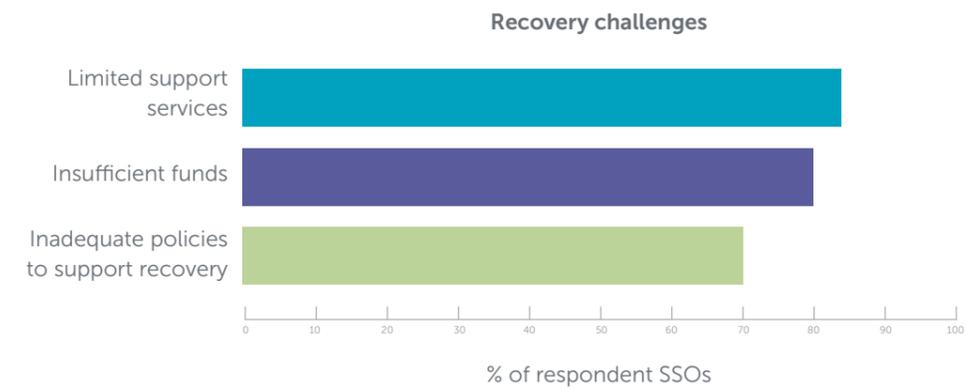


Fig 35. Most frequently reported challenges for recovery activities

“ The Bulgarian Society of Neurology supports and works with neurologists, general practitioners and foundations, such as the National Heart to Heart Network. Together we raise awareness about stroke prevention and increase understating of stroke symptoms. ”

Acad. Prof. Dr. Ivan Milanov, Director St.Naum Neurological Hospital, Chairman Bulgarian Society of Neurology

Breaking it down by region, the challenges most frequently reported by respondent SSOs to delivering recovery activities are:

**Sub-Saharan Africa/Middle East/East Mediterranean**

- Insufficient funds – 100% (22/22)
- Limited support services – 82% (18/22)
- Inadequate policies to support recovery – 82% (18/22)

**Americas**

- Limited support services – 83% (15/18)
- Inadequate policies to support recovery – 83% (15/18)
- Insufficient funds – 72% (13/18)

**Europe**

- Limited support services – 82% (28/34)
- Insufficient funds – 74% (25/34)
- Inadequate policies to support recovery – 71% (24/34)

**Asia/Oceania**

- Limited support services – 86% (12/14)
- Insufficient funds – 79% (11/14)
- Inadequate policies to support recovery – 57% (8/14)

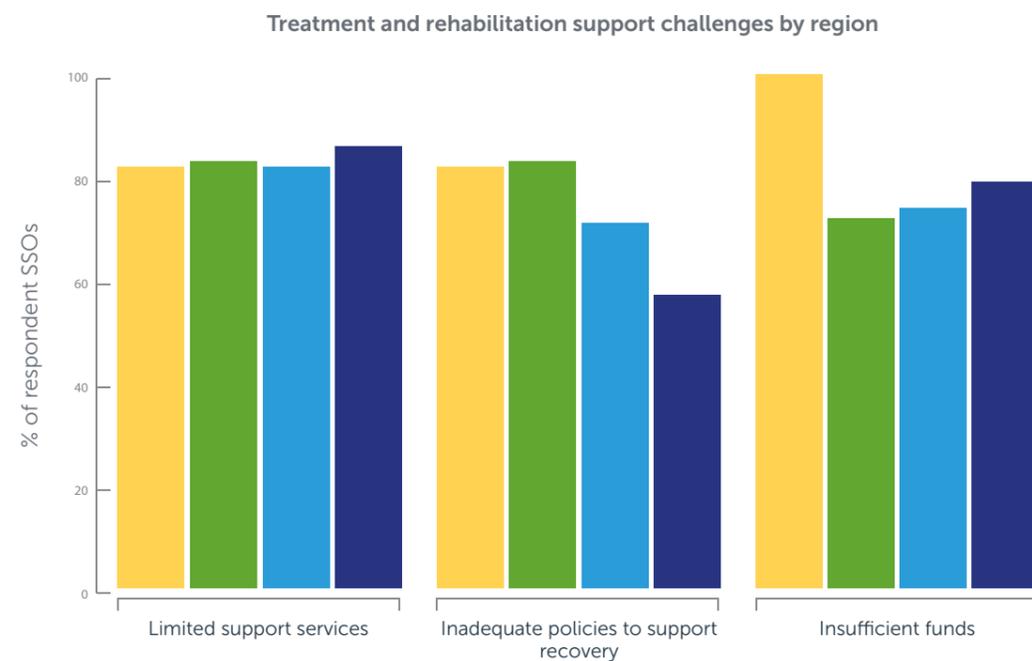


Fig 36. Most frequently reported challenges for recovery activities by region

**B. Data collection**

The questionnaire asked whether SSOs collect data on the number of people (e.g., stroke survivors, carers and family, and children who have had a stroke) that their activities reach. Overall, 56% (49/87) of respondent SSOs reported that they engage in data collection, and they do so using a wide variety of data collection methods. 67% (33/49) of these SSOs disclosed the number of people that they reach. However, it is not possible to make comparisons between this data as different units of measurement were used (e.g., daily, per event, annually) and different mechanisms are referenced (e.g., face to face, online, through media).

The high degree of variability in responses indicates gaps in the comprehensive and consistent capturing of activity and output data by SSOs. This highlights a key challenge for SSOs in their ability to demonstrate impact. Without evidence of impact SSOs may face difficulties in raising their profile and attracting sustainable funding.



**56%** of SSOs engage in data collection

Region	% of SSOs collecting data on the number of people they reach	Data collection method
<b>Sub-Saharan Africa/Middle East/East Mediterranean</b>	68%	National register, during events, during registration for the national health insurance scheme, on visits, by interview, questionnaires, through service delivery
<b>Americas</b>	58%	User database, questionnaires, website statistics, registration, events
<b>Europe</b>	45%	Activities register, database, member registration, web statistics, annual and online surveys, monitoring telephone, email contacts
<b>Asia/Oceania</b>	62%	Online platforms, social media, helpline, service clients with consent, patient register, activity register, referral database

Fig 37. SSO data collection

### C. Proposed solutions

Using a multiple choice question, the SSOs were asked to identify solutions to the challenges they face in delivering activities across the stroke care pathway. The most frequently reported solutions by all respondent SSOs are:

- Increased partnership between SSOs and government, clinicians, academics – 88% (79/90)
- Improved skills in fundraising – 51% (46/90)
- Improved skills in advocacy and campaigning – 46% (41/90)
- Tools to gather data on SSO activity outcomes and impact - 39% (35/90)
- Improved data on incidence and prevalence – 29% (26/90)
- Increased collaboration between SSOs – 27% (24/90)

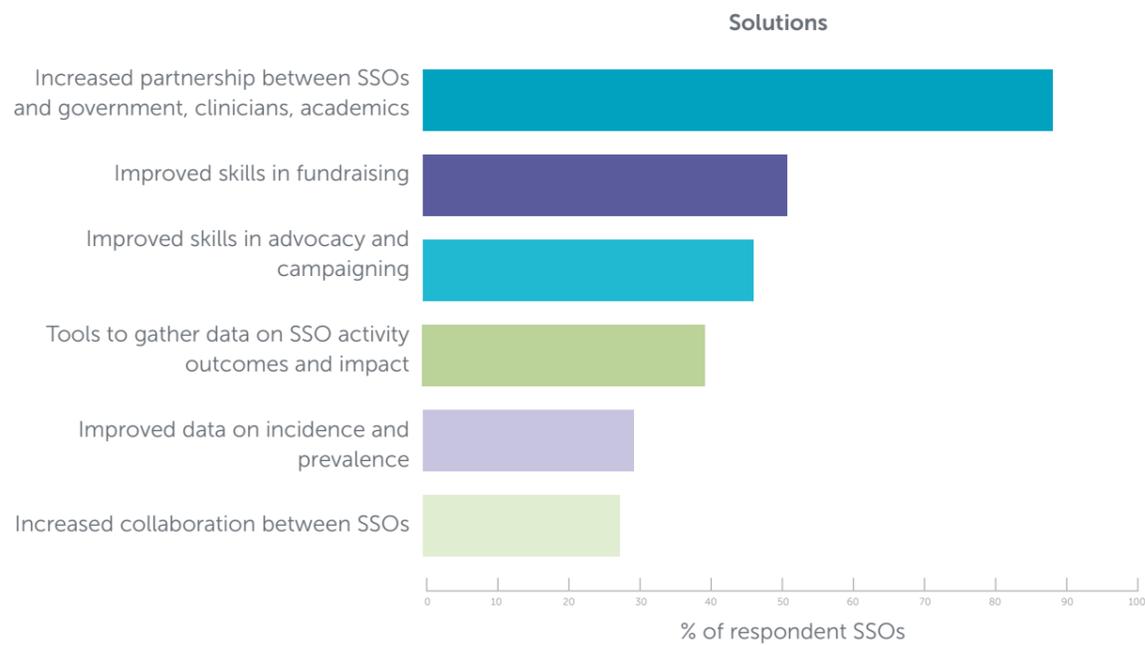


Fig 38. Most frequently reported solutions to the challenges faced

“ Stroke Association Support Network Ghana’s Community Life after Stroke Program has been the centre of hope and connection to rebuild our lives after a stroke within the community, where access to health care and support is a big challenge ”

Mr Samuel Sedodo, Chairperson for stroke survivors, Stroke Association Support Network Ghana

The three most frequently identified solutions are consistent across all regions, except Europe, where ‘Tools to gather data on SSO activity outcomes and impact’ replaces ‘Improved skills in fundraising’. This indicates that there is a strong desire for partnership and capacity building amongst the SSOs across all four regions.

#### Sub-Saharan Africa/Middle East/East Mediterranean

- Increased partnership between SSOs and government, clinicians, academics – 82% (18/22)
- Improved skills in fundraising – 73% (16/22)
- Improved skills in advocacy and campaigning – 50% (11/22)

#### Americas

- Increased partnership between SSOs and government, clinicians, academics – 83% (15/18)
- Improved skills in fundraising – 50% (9/18)
- Improved skills in advocacy and campaigning – 44% (8/18)

#### Europe

- Increased partnership between SSOs and government, clinicians, academics – 94% (34/36)
- Tools to gather data on SSO activity outcomes and impact – 42% (15/36)
- Improved skills in advocacy and campaigning – 39% (14/36)

#### Asia/Oceania

- Increased partnership between SSOs and government, clinicians, academics – 86% (12/14)
- Improved skills in fundraising – 57% (8/14)
- Improved skills in advocacy and campaigning – 57% (8/14)

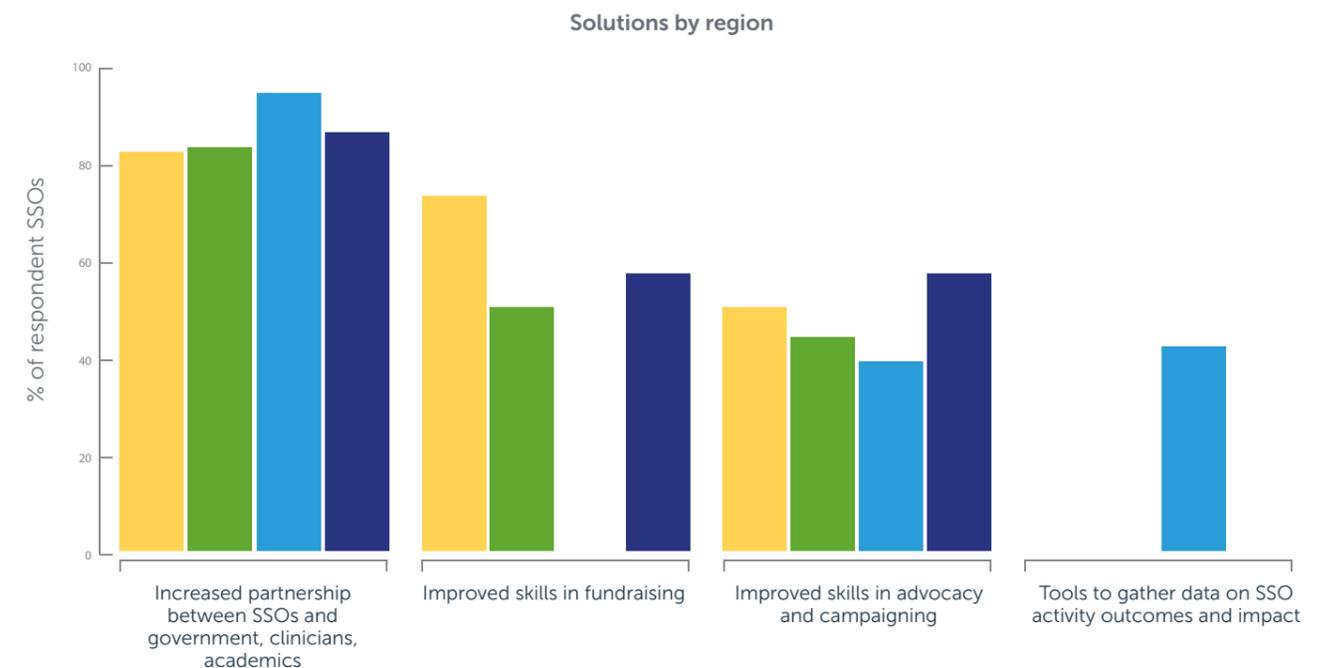


Fig 46. Most frequently reported solutions to the challenges faced by region

## D. Conclusion and opportunities

The SSO Global Mapping has shown that these organizations are operating across the world, in both high resource and low resource settings, and delivering activities across the stroke care pathway. The mix in the founders of SSOs reveals existing collaboration between medical professionals, people with lived experience and the lay community. SSOs are mobilizing large numbers of people as volunteers in awareness-raising and service delivery. They are also connecting beyond local and national boundaries to build a truly global movement for stroke.

While the number of SSOs is growing, this mapping suggests that for SSOs to maximize their contribution to driving improved stroke outcomes globally and to broader NCD global agendas, capacity building, increased partnership and collaboration, and funding opportunities require considerable investment. Many of these organizations are working with limited resources in contexts where there are significant gaps in provision across the stroke care pathway.

This SSO Global Mapping contains insights that, with further analysis and focused research, can inform the WSO's capacity building activities for SSOs. In particular, benchmarking of SSO stroke awareness, rehabilitation and recovery activities against evidence based guidelines.

In response to the challenges that SSOs reported and the solutions they identified, there are a number of actions that need to be prioritized.

Focus	Action	Opportunity
SSO internal structure	Ongoing training and accompaniment in organizational sustainability: <ul style="list-style-type: none"> <li>Context analysis</li> <li>Strategic planning</li> <li>Resource engagement and management</li> <li>Meaningful involvement of people with lived experience</li> </ul>	Share good practice and resources from across the WSO and its network. The <a href="#">Stroke Connector</a> platform is a key resource to do this.  Leverage WSO education and congress activities to support SSO organizational and skills development, and to highlight their role and value.
SSO performance	Skills to measure performance: <ul style="list-style-type: none"> <li>Data collection – user, engagement, feedback and outcomes</li> <li>Data analysis and reporting</li> <li>Audit of interventions against evidence based guidelines</li> </ul>	Signpost SSOs to in-country organizational and programme development opportunities.  Further leveraging of existing collaboration between SSOs, academics and health care professionals.
External linkages	Building successful relationships and communicating with impact: <ul style="list-style-type: none"> <li>Communication strategy</li> <li>Advocacy cycle</li> <li>Fundraising strategy</li> </ul>	Continue to facilitate SSO links with research groups globally, particularly in LMICs.

# Annex 1

## SSO Mapping Questionnaire

### Organization domain

1	What is the full name of your SSO?	
2	What is the name of the key contact and contact details?	
3	In which country does your organisation work?	
4	What is the incidence and prevalence of stroke in your country?	
5	What year was your organisation established?	
6	Is your organisation legally registered and with what authority?	
7	What is the vision and mission of your organisation? Where is this publicised? Website/brochure? (please include online links where available)	
8	What conditions does your SSO focus on – stroke only or stroke and other conditions?	
9	What is the background of the founder of your organisation – stroke survivor/family member/medic/other?	
10	How is your organisation governed? Board, Committee? Do you have governance documents that you could share such as act of incorporation, statute, charter?	
11	How do you include people affected by stroke in decision making in your SSO? Members of the Board, patient committees, project focus groups?	
12	At which level does your organisation focus the majority of its activities? (put in order 1 most, 5 least)	<ul style="list-style-type: none"> <li>• Community level</li> <li>• National level</li> <li>• Regional level (continental/sub-continental)</li> <li>• Global</li> <li>• Other (specify)</li> </ul>
13	What was the total number of paid staff in your organisation in 2018?	

14	What was the total number of volunteers in your organisation in 2018?	
15	Are you a membership organisation? If so how many members did you have in 2018?	
16	Is your SSO a member of an alliance or membership organisation (eg SAFE, WSO, NCD Alliance)?	
17	What was your income (this includes total donations) in 2018?	
18	What were your funding sources in 2018? Do you receive government funding Y/N	
19	What is your website address?	
20	What is your twitter address?	
21	Do you give consent for your answers to be shared in an SSO mapping report?	

## Activity domain

1	Prevention awareness. What areas do you have the most focus on? (Select top 3)	<ul style="list-style-type: none"> <li>Promotion of FAST</li> <li>Local and national public education on risk factors</li> <li>Screening events</li> <li>Secondary prevention information and advice</li> <li>Other (please specify)</li> </ul>
2	Treatment and rehabilitation. What areas do you have the most focus on? (Select top 3)	<ul style="list-style-type: none"> <li>Rehabilitation activities</li> <li>Funding research</li> <li>Advocacy – including patient and policy and influencing</li> <li>Other (please specify)</li> </ul>
3	Recovery. What areas do you have the most focus on? (Select top 3)	<ul style="list-style-type: none"> <li>Information materials</li> <li>Support groups</li> <li>Return to work</li> <li>Self-management tools</li> <li>Home visits</li> <li>Signposting to other organisations and services</li> <li>Funding research</li> <li>Advocacy – including patient and policy and influencing</li> <li>Other (please specify)</li> </ul>

4	End of life. Do you provide palliative care?	
5	Do you participate in research projects? If so please share details Do you provide palliative care?	
6	In 2018 which three activities of your SSO were the most successful and why?	<ul style="list-style-type: none"> <li>Activity:</li> <li>What was the success:</li> <li>Why:</li> </ul>
7	Which groups are the target beneficiaries/audience of your work (Select top 3)	<ul style="list-style-type: none"> <li>Stroke survivors</li> <li>Carers</li> <li>Family members, including children</li> <li>Children who have had a stroke</li> <li>Public</li> <li>Government</li> <li>Other (please specify)</li> </ul>
8	Do you collect data on the number of stroke survivors, carers and family, and children who have had a stroke that your activities reach? If so, how many people do you reach? How do you collect data?	
9	What challenges do you face in raising awareness of stroke in your country? (Select top 3)	<ul style="list-style-type: none"> <li>Lack of data on incidence and prevalence</li> <li>Stigma and discrimination</li> <li>Low health literacy</li> <li>Inadequate policies for stroke prevention</li> <li>Inadequate human resource</li> <li>Lack of information resources</li> <li>No national health promotion initiatives</li> <li>Other (please specify)</li> </ul>
10	What challenges do you face in supporting stroke treatment and rehabilitation in your country? (Select top 3)	<ul style="list-style-type: none"> <li>Lack of data on incidence and prevalence</li> <li>Low awareness of stroke symptoms and emergency response</li> <li>Stigma and discrimination</li> <li>Inadequate strategies for stroke treatment and rehabilitation</li> <li>No stroke units</li> <li>Inadequate recognition of rehabilitation</li> <li>Inadequate human resource</li> <li>Other (please specify)</li> </ul>

## Annex 2 Respondents

WSO Member 2018
WSO and SAFE Member 2018
SAFE Member 2018
Non Member of WSO and SAFE 2018

11	What challenges do you face in supporting stroke recovery in your country? (Select top 3)	<ul style="list-style-type: none"> <li>• Stigma and discrimination</li> <li>• Limited support services</li> <li>• Inadequate social protection</li> <li>• Inadequate policies to support recovery</li> <li>• Insufficient funds</li> <li>• Other (please specify)</li> </ul>
12	What do you think are the possible solutions to the challenges you face in activities across the stroke pathway (Select top 3)	<ul style="list-style-type: none"> <li>• Improved data on incidence and prevalence</li> <li>• Tools to gather data on SSO activity outcomes and impact</li> <li>• Increased collaboration between SSOs</li> <li>• Increased partnership between SSOs and government, clinicians, academics</li> <li>• Improved skills in advocacy and campaigning</li> <li>• Improved skills in fundraising</li> <li>• Other (please specify)</li> </ul>

### Sub-Saharan Africa/Middle East/East Mediterranean – 22

1	Cameroon	Azur Vigilance Cameroun
2	Ghana	Stroke Association Support Network Ghana
3	Ghana	Stroke Aid Foundation
4	Iran	Stroke Support Organization- East Azerbaijan
5	Kenya	Stroke Association Of Kenya
6	Kenya	Stroke and Hypertension Association
7	Nigeria	Acha Memorial Foundation
8	Nigeria	IDA Stroke Awareness Foundation
9	Nigeria	Michael and Francisca Foundation
10	Nigeria	Road 2 Recovery Foundation
11	Nigeria	Stroke Action Nigeria
12	Nigeria	Stroke Care International Initiative
13	Nigeria	Stroke Control Innovations Initiative of Nigeria
14	Seychelles	Seychelles Stroke Foundation
15	South Africa	Helderberg Stroke Support Group
16	South Africa	Stroke Support Group Pretoria
17	South Africa	Heart And Stroke Foundation South Africa
18	South Africa	The Stroke Survivors Foundation
19	Tanzania	Joel Samson Ruvugo Traders
20	Tanzania	Tanzania Heart Club
21	Uganda	Stroke Foundation Uganda
22	Zimbabwe	Stroke Organisation Zimbabwe

### Americas – 19

23	Barbados	Heart and Stroke Foundation
24	Brazil	Mineira Stroke Association
25	Brazil	Associação Brasil AVC
26	Brazil	Acao AVC
27	Brazil	Brazilian Stroke Network
28	Canada	Heart and Stroke Foundation
29	Canada	March of Dimes

30	Dominican Republic	Fundación Dominicana de Accidente Cerebral
31	Jamaica	Jamaica Stroke Alliance
32	Mexico	Asociación Nacional Contra el Infarto cerebral, A.C
33	United States	Healings in Motion
34	United States	International Alliance for Pediatric Stroke
35	United States	Stroke Focus
36	United States	Stroke Recovery Foundation
37	United States	Survivors 4 Survivors
38	United States	YoungStroke, Inc
39	United States	901 Stroke Alliance
40	United States	American Stroke Association
41	Latin America & Caribbean	Latin American and Caribbean Stroke Network

**Europe – 37**

42	Belgium	Belgian Stroke Council
43	Bulgaria	National Network Heart for Heart Foundation
44	Catalonia/Spain	Fundacio Ictus
45	Croatia	Croatian Stroke Society
46	Croatia	Mozdani Val
47	Cyprus	Cyprus Stroke Association
48	Czech Republic	Cerebrum
49	Czech Republic	Ergo-Activ
50	Denmark	Hjernesagen - The Danish Stroke Association
51	Faroe Islands	Heilafelagið
52	Finland	Aivoliitto
53	Germany	Stiftung Deutsche Schlaganfall-Hilfe
54	Greece	Hellenic Action for Stroke
55	Hungary	National Stroke ( Prevention & Rehabilitation) League
56	Iceland	HEILAHEILL
57	Ireland	Croí, the West of Ireland Cardiac & Stroke Foundation
58	Ireland	Irish Heart Foundation
59	Israel	Neeman Association For Stroke Survivors
60	Italy	Associazione Lotta Ictus Cerebrale (ALICE)
61	Latvia	ParSirdi.lv

62	Luxembourg	Bletz asbl
63	Netherlands	Patiëntvereniging Hersenletsel.nl
64	North Macedonia	Association for fight against stroke
65	Norway	Norsk forening for slagrammede
66	Portugal	Portugal AVC
67	Russian Federation	Orbi Foundation Russia
68	Serbia	Serbian Stroke Association
69	Slovakia	Porazka.sk
70	Slovenia	Slovenian Stroke Support Organisation
71	Sweden	Strokeföreningen Malmö
72	Sweden	STROKE-Riksförbundet
73	Switzerland	FRAGILE Suisse
74	Ukraine	Ukrainian Anti-Stroke Association
75	United Kingdom	Different Strokes
76	United Kingdom	Stroke Association
77	United Kingdom	Stroke And Diabetes Education and Aid Foundation
78	Europe	Stroke Alliance For Europe

**Asia/Oceania – 14**

79	Australia	Australia Stroke Foundation
80	Bangladesh	Bangladesh Stroke Association
81	China	Red Bracelet Volunteers Corps
82	Fiji	CounterStroke
83	India	Bangalore Stroke Support Group
84	India	Dr Bindu Menon Foundation
85	India	Stroke Foundation Of Bengal
86	Japan	Japan Stroke Association
87	Malaysia	National Stroke Association of Malaysia
88	Nepal	Nepal Stroke Association
89	New Zealand	Stroke Central Region Inc
90	New Zealand	Stroke Foundation of NZ
91	Singapore	Singapore National Stroke Association
92	Sri Lanka	Stroke Support Organization for Sri Lankans

## Annex 3

Sub-Saharan Africa/Middle East/East Mediterranean	Website	Twitter
Azur Vigilance Cameroun		
Stroke Association Support Network Ghana	<a href="http://www.care.sasnetghana.org">www.care.sasnetghana.org</a>	@ghbeatstroke
Stroke Aid Foundation	<a href="http://www.strokeaidfoundation.org">www.strokeaidfoundation.org</a>	
Stroke Support Organization - East Azerbaijan	<a href="http://www.sso-ea.com">www.sso-ea.com</a>	
Stroke Association Of Kenya	<a href="http://www.strokeassociationofkenya.or.ke">www.strokeassociationofkenya.or.ke</a>	@saokenya1
Stroke and Hypertension Association	<a href="http://www.strokehypertension.org">www.strokehypertension.org</a>	@Strokehyperten1
Acha Memorial Foundation	<a href="http://www.achafoundation.com">www.achafoundation.com</a>	@AchaMFoundation @GoMasterStroke
IDA Stroke Awareness Foundation	<a href="http://www.idastrokefoundation.org">www.idastrokefoundation.org</a>	@IDASAFoundation
Michael and Francisca Foundation	<a href="http://www.michaelfranciscafoundation.org">www.michaelfranciscafoundation.org</a>	@micffoundation
Road 2 Recovery Foundation	<a href="http://www.r2rteam.com">www.r2rteam.com</a>	@road2recover @waka2cure
Stroke Action Nigeria	<a href="http://www.strokeactionnigeria.com">www.strokeactionnigeria.com</a>	@strokenigeria
Stroke Care International Initiative	<a href="http://www.strokecareinternational.org">www.strokecareinternational.org</a>	@strokecare1
Stroke Control Innovations Initiative of Nigeria		
Seychelles Stroke Foundation		
Helderberg Stroke Support Group	<a href="http://www.hssg.org.za">www.hssg.org.za</a>	
Stroke Support Group Pretoria	<a href="http://www.strokesupport.co.za">www.strokesupport.co.za</a>	
Heart And Stroke Foundation South Africa	<a href="http://www.heartfoundation.co.za">www.heartfoundation.co.za</a>	@Saheartstroke
The Stroke Survivors Foundation	<a href="http://www.strokesurvivors.org.za">www.strokesurvivors.org.za</a>	@strokesurvivors
Joel Samson Ruvugo Traders	<a href="http://www.jsr.co.tz">www.jsr.co.tz</a>	@JoelRUVUGO
Tanzania Heart Club		Stroke Organisation Zimbabwe
Stroke Foundation Uganda	<a href="http://www.strokefoundationuganda.org">www.strokefoundationuganda.org</a>	@StrokeFoundation2
Stroke Organisation Zimbabwe		@strokezim

Americas	Website	Twitter
Heart and Stroke Foundation Canada	<a href="http://www.heartandstroke.ca">www.heartandstroke.ca</a>	@heartandstroke @HSF_science
Mineira Stroke Association	<a href="http://www.amavc.com.br">www.amavc.com.br</a>	
Associação Brasil AVC	<a href="http://www.abavc.org.br">www.abavc.org.br</a>	@ABAVC_Oficial
Acao AVC	<a href="http://www.acaoavc.org.br">www.acaoavc.org.br</a>	
Brazilian Stroke Network	<a href="http://www.redebrasilavc.org.br">www.redebrasilavc.org.br</a>	@RBAVC
Heart and Stroke Foundation	<a href="http://www.heartandstroke.ca">www.heartandstroke.ca</a>	@heartandstroke @HSF_science

March of Dimes Canada	<a href="http://www.marchofdimes.ca">www.marchofdimes.ca</a>	@marchofdimescda
Fundación Dominicana de Accidente Cerebral		@fundacerd
Jamaica Stroke Alliance	<a href="http://www.jamaicastrokealliance.org">www.jamaicastrokealliance.org</a>	
Asociación Nacional Contra el Infarto cerebral, A.C	<a href="http://www.ancic.org.mx">www.ancic.org.mx</a>	@ANCICmx
Healings in Motion	<a href="http://www.healingsinmotion.org">www.healingsinmotion.org</a>	@Brain2Retain
International Alliance for Pediatric Stroke	<a href="http://www.iapediatricstroke.org">www.iapediatricstroke.org</a>	@strokepediatric
Stroke Focus	<a href="http://www.strokefocus.net">www.strokefocus.net</a>	
Stroke Recovery Foundation	<a href="http://www.strokerecoveryfoundation.org">www.strokerecoveryfoundation.org</a>	@StrokeVictor
Survivors 4 Survivors	<a href="http://www.pssdan.com">www.pssdan.com</a>	
YoungStroke, Inc	<a href="http://www.youngstroke.org">www.youngstroke.org</a>	
901 Stroke Alliance	<a href="http://www.stompoutstroke901.com">www.stompoutstroke901.com</a>	
American Stroke Association	<a href="http://www.stroke.org">www.stroke.org</a>	@American_Stroke
Latin American and Caribbean Stroke Network	<a href="https://www.facebook.com/Rede-Latino-Americana-e-Caribenha-de-AVC-215772695670000/">www.facebook.com/Rede-Latino-Americana-e-Caribenha-de-AVC-215772695670000/</a>	

Europe	Website	Twitter
Belgian Stroke Council	<a href="http://www.belgianstrokecouncil.be">www.belgianstrokecouncil.be</a>	@BelgianStrokeCo
National Network Heart for Heart Foundation	<a href="http://www.heartforheart.bg">www.heartforheart.bg</a>	
Fundacio Ictus	<a href="http://www.fundacioictus.com">www.fundacioictus.com</a>	@Fundacioictus
Croatian Stroke Society	<a href="http://www.mozdaniudar.hr">www.mozdaniudar.hr</a>	@fightyourstroke @hdp mu
Mozdani Val	<a href="http://www.mozdanival.hr">www.mozdanival.hr</a>	
Cyprus Stroke Association	<a href="http://www.stroke.org.cy">www.stroke.org.cy</a>	@StrokeCyprus
Cerebrum	<a href="http://www.cerebrum2007.cz">www.cerebrum2007.cz</a>	
Ergo-Activ	<a href="http://www.ergoaktiv.cz">www.ergoaktiv.cz</a>	
Hjernesagen - The Danish Stroke Association	<a href="http://www.hjernesagen.dk">www.hjernesagen.dk</a>	@Hjernesagen
Heilafelagið		
Aivoliitto	<a href="http://www.aivoliitto.fi">www.aivoliitto.fi</a>	@Aivoliitto
Stiftung Deutsche Schlaganfall-Hilfe	<a href="http://www.schlaganfall-hilfe.de">www.schlaganfall-hilfe.de</a>	@Schlaganfall_Dt
Hellenic Action for Stroke	<a href="http://www.strokesupport.gr">www.strokesupport.gr</a>	
National Stroke ( Prevention & Rehabilitation) League	<a href="http://www.strokeliga.blogspot.com">www.strokeliga.blogspot.com</a>	
HEILAHEILL	<a href="http://www.heilaheill.is">www.heilaheill.is</a>	@heilaheill
Croi, the West of Ireland Cardiac & Stroke Foundation	<a href="http://www.croi.ie">www.croi.ie</a>	@CroiHeartStroke
Irish Heart Foundation	<a href="http://www.irishheart.ie">www.irishheart.ie</a>	@Irishheart_ie
Neeman Association For Stroke Survivors	<a href="http://www.neeman.org.il">www.neeman.org.il</a>	@neemanstroke
Associazione Lotta Ictus Cerebrale (ALICE)	<a href="http://www.aliceitalia.org">www.aliceitalia.org</a>	@aliceitalia2011

ParSirdi.lv	<a href="http://www.parsirdi.lv">www.parsirdi.lv</a>	@ParSirdi
Bletz asbl	<a href="http://www.bletz.lu">www.bletz.lu</a>	
Patiëntenvereniging Hersenletsel.nl	<a href="http://www.hersenletsel.nl">www.hersenletsel.nl</a>	@NLHersenletsel
Association for fight against stroke	<a href="http://www.mozocenudar.mk">www.mozocenudar.mk</a>	
Norsk forening for slagrammede	<a href="http://www.slagrammede.org">www.slagrammede.org</a>	@nfs_norway
Portugal AVC	<a href="http://www.portugalavc.pt">www.portugalavc.pt</a>	
Orbi Foundation Russia	<a href="http://www.orbifond.ru">www.orbifond.ru</a>	
Serbian Stroke Association	<a href="http://www.mozdaniudar.org">www.mozdaniudar.org</a>	@strokeserbia
Porazka.sk	<a href="http://www.porazka.sk">www.porazka.sk</a>	
Slovenian Stroke Support Organisation	<a href="http://www.zdruzenjecvb.com">www.zdruzenjecvb.com</a>	
Strokeföreningen Malmö	<a href="http://www.strokemalmo.se">www.strokemalmo.se</a>	
STROKE-Riksförbundet	<a href="http://www.strokeforbundet.se">www.strokeforbundet.se</a>	@Strokeforbundet
FRAGILE Suisse	<a href="http://www.fragile.ch">www.fragile.ch</a>	@FRAGILE_Suisse
Ukrainian Anti-Stroke Association	<a href="http://www.uabi.org.ua">www.uabi.org.ua</a>	
Different Strokes	<a href="http://www.differentstrokes.co.uk">www.differentstrokes.co.uk</a>	@diffstrokes
Stroke Association	<a href="http://www.stroke.org.uk">www.stroke.org.uk</a>	@TheStrokeAssoc
Stroke And Diabetes Education and Aid Foundation	<a href="http://www.sadeaf.com">www.sadeaf.com</a>	
Stroke Alliance For Europe	<a href="http://www.safestroke.eu">www.safestroke.eu</a>	@StrokeEurope
<b>Asia/Oceania</b>		
	<b>Website</b>	<b>Twitter</b>
Australia Stroke Foundation	<a href="http://www.strokefoundation.org.au">www.strokefoundation.org.au</a>	@strokefdn
Bangladesh Stroke Association	<a href="http://www.stroke.dgbangla.com">www.stroke.dgbangla.com</a>	
Red Bracelet Volunteers Corps		
CounterStroke Fiji		
Bangalore Stroke Support Group	<a href="http://www.bssg.in">www.bssg.in</a>	
Dr Bindu Menon Foundation	<a href="http://www.drbindumenon.com">www.drbindumenon.com</a>	@bindumenon2013
Stroke Foundation Of Bengal	<a href="http://www.strokefoundation.in">www.strokefoundation.in</a>	@strokefndbengal
Japan Stroke Association	<a href="http://www.jsa-web.org">www.jsa-web.org</a>	
National Stroke Association of Malaysia	<a href="http://www.nasam.org">www.nasam.org</a>	
Nepal Stroke Association	<a href="http://www.strokenepal.org">www.strokenepal.org</a>	@StrokeNepal
Stroke Central Region Inc	<a href="http://www.strokecentral.org.nz">www.strokecentral.org.nz</a>	@StrokeCentralNZ
Stroke Foundation of NZ	<a href="http://www.stroke.org.nz">www.stroke.org.nz</a>	@Stroke_nz
Singapore National Stroke Association	<a href="http://www.snsa.org.sg">www.snsa.org.sg</a>	
Stroke Support Organization for Sri Lankans		

World Stroke Organization  
7, rue Francois Versonnex  
PO Box 6053  
CH 1211 Geneva 6, Switzerland  
[www.world-stroke.org](http://www.world-stroke.org)