



World Stroke
Organization

Stroke Support Organization Global Mapping **SUMMARY REPORT**

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On Behalf of the World Stroke Organization Stroke Support Organization Committee



Acknowledgements

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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

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

Executive summary

Stroke is a leading cause of death and disability globally. There are over 13.7 million new strokes each year¹. 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 lifetime².

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.

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

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.

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.

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).

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

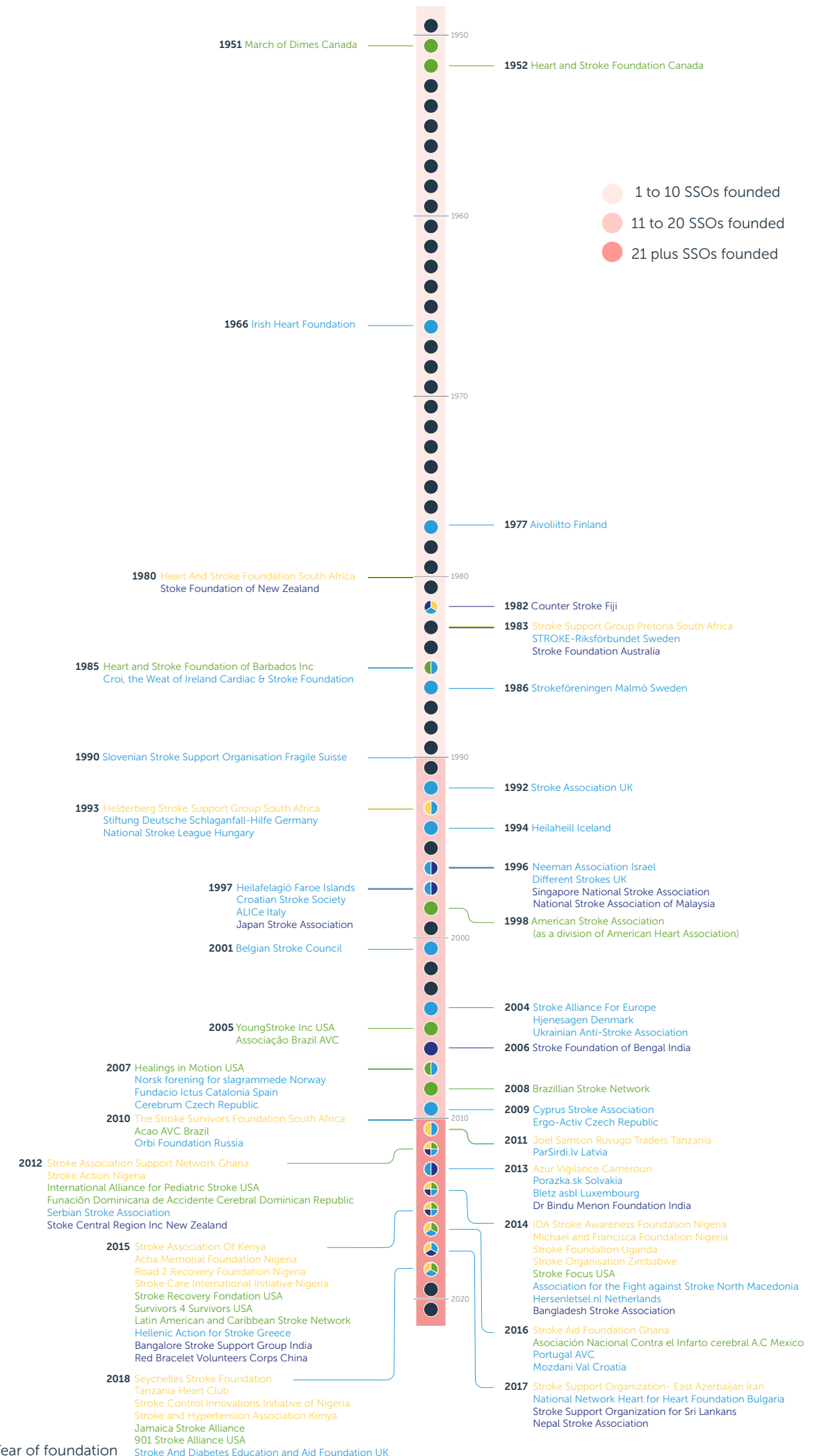


Fig 1. Year of foundation

Key messages

1. 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.

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.

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.

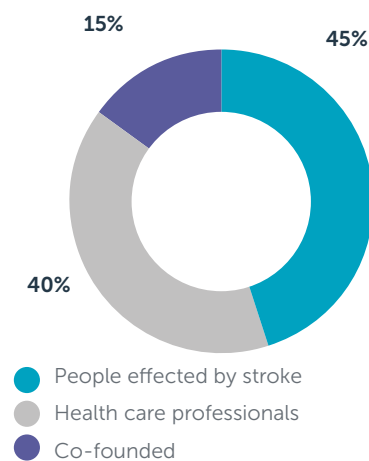


Fig 2. SSO founder

Registration (Legal status)

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.

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.

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.

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

Research

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



60% of respondent SSOs participate in research

2. 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.

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, Stroke Alliance for Europe (SAFE) and the Latin American and Caribbean Stroke Network, reporting that they have society members. For respondent SSOs with individual members, 53% (29/55) have 200 or more members.

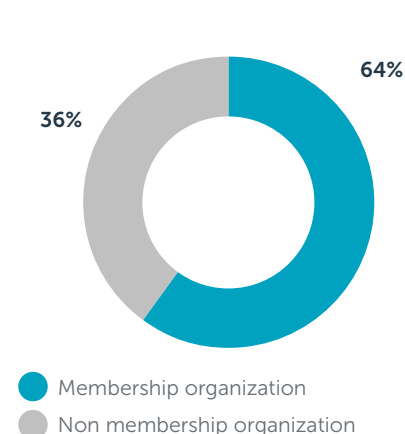


Fig 3. SSO membership status

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.

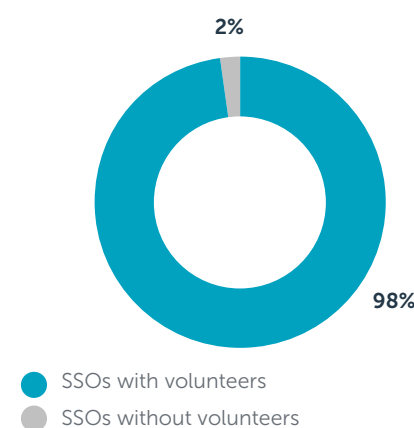


Fig 4. SSOs with volunteers

“The Stroke Association – as our only dedicated stroke charity – is absolutely vital to the success of stroke research in the UK; at a personal level, their funding has enabled me to train as a research-active stroke neurologist, and to develop my own stroke research projects as a more senior researcher.”

Professor David Werring, Professor of Clinical Neurology, UCL Institute of Neurology, UK

3. SSOs are engaging beyond their local and geographic boundaries.

Membership of other organizations and alliances with shared agendas is common. SSOs in LMICs in particular are leveraging their membership of international organizations.

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 toward 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.

Alliances

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



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



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Website and Twitter

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



90% of the SSOs have an organization website



58% of the SSOs have a Twitter account

“ The empowerment of stroke survivors to take charge of their lives and to make as full a recovery as possible after stroke is a topic very close to my heart and the foundation of our work at the National Stroke Organisation of Malaysia.

Janet Yeo, stroke survivor and founder of The National Stroke Organisation of Malaysia

”



4. 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.

Paid Staff

Over half (57%, 52/91) of the respondent SSOs reported having paid staff. The ability to pay staff is likely to increase the potential of an SSO to recruit personnel with the specific skills needed to increase the impact of the organization. It is also likely to enable the SSO to retain staff and increase the stability of the organization. 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.

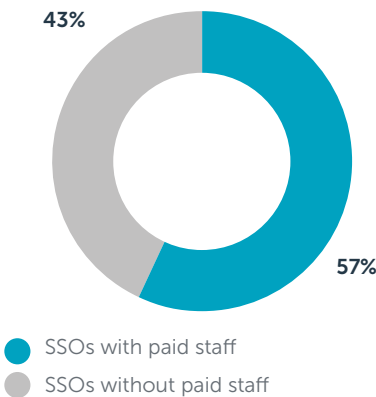


Fig 5. SSOs with paid staff

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.

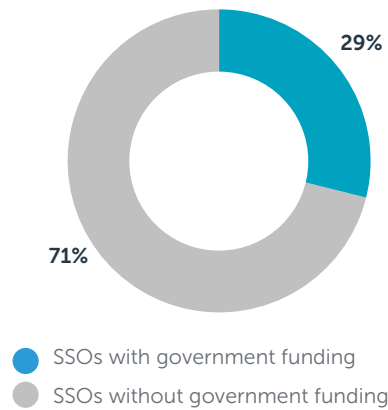


Fig 6. SSOs with government funding

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 our fight against stroke, the focus of Stroke Aid Foundation is on prevention. However, when a stroke does occur, we work to remove the barriers that stroke survivors face in accessing rehabilitation, including stigma, cost and availability of therapists ”

Hosea Boakye, Senior Physiotherapist, Ghana

5. SSOs face a number of challenges in their work to raise awareness of stroke, support treatment and rehabilitation, and assist recovery.

Inadequate national strategies and policies for stroke prevention, treatment and recovery were identified by respondent SSOs as major challenges.

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 were further challenges identified by respondent SSOs.

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)

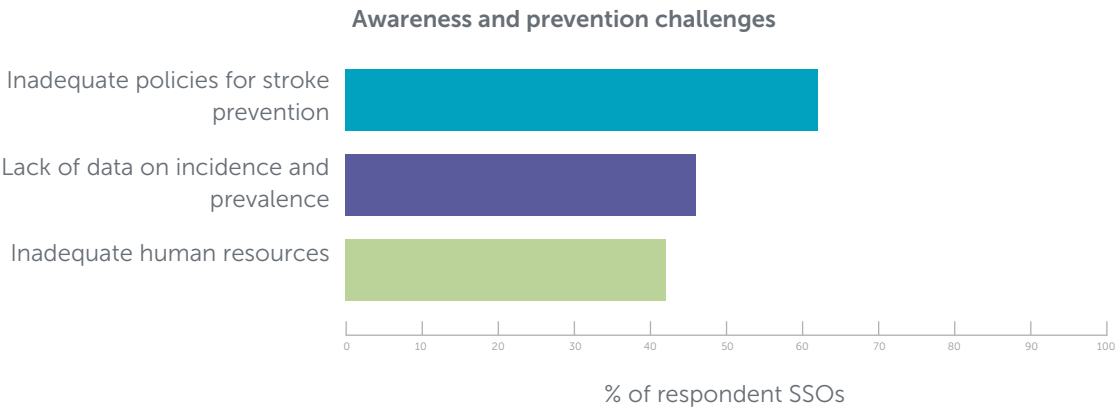


Fig 7. Most frequently reported challenges for awareness and prevention activities

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)

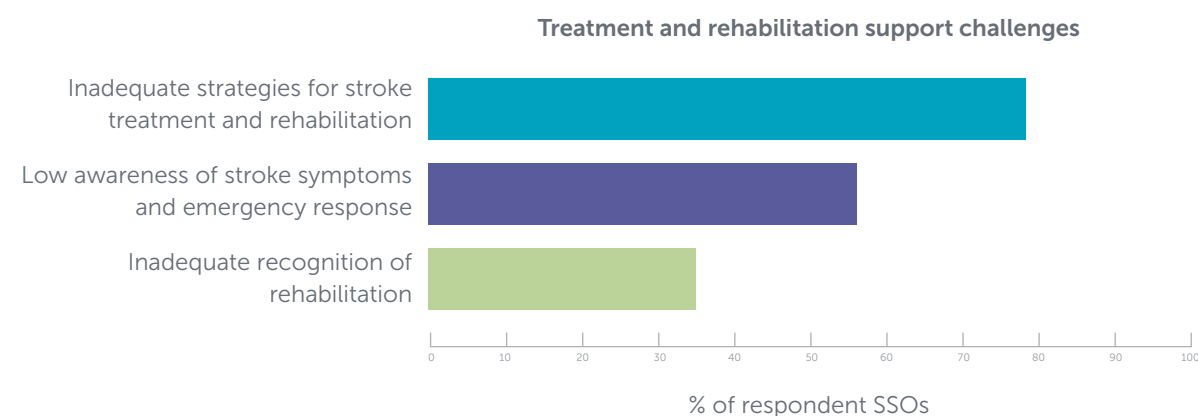


Fig 8. Most frequently reported challenges for treatment and rehabilitation support activities

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

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

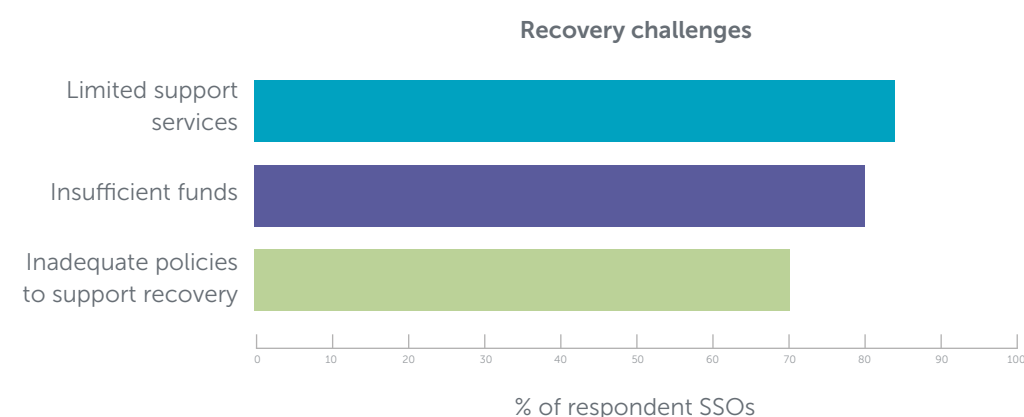


Fig 9. Most frequently reported challenges for recovery activities

6. SSOs identified a number of solutions to overcome the challenges they face.

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)

The top 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.



Fig 10. Most frequently identified solutions to the challenges faced

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.

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.

“

A strong alliance between physicians and the national patient organisations is key when approaching politicians. It helps to underline the fact that stroke and stroke care are issues affecting the whole population and ultimately will lead to long-term improvements in the health care system

”

Dr Valeria Caso, neurologist, Italy. SAFE and European Stroke Organisation Stroke Action Plan for Europe 2018-2030 working session

Focus	Action	Opportunity
SSO internal structure	Ongoing training and accompaniment in organizational sustainability: <ul style="list-style-type: none"> Context analysis Strategic planning Resource engagement and management Meaningful involvement of people with lived experience 	Share good practice and resources from across the WSO and its network. The Stroke Connector 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"> Data collection – user, engagement, feedback and outcomes Data analysis and reporting Audit of interventions against evidence based guidelines 	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"> Communication strategy Advocacy cycle Fundraising strategy 	Continue to facilitate SSO links with research groups globally, particularly in LMICs.



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