



# Stroke Support Organization **Toolkit**

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# Foreward

As the only global organization solely focused on stroke, at the WSO we are committed to working with all our members including those with clinical, research and lived expertise. One of WSO's strategic priorities is to engage with health care professionals, stroke support organizations and people with lived experience to increase understanding of the importance of quality stroke care across the continuum.

Over the past few years, we have seen a significant increase in our stroke support organization members. The work of these organizations in every region of the world to raise stroke awareness, deliver life after stroke services, and influence policy and research funding is vital.

From raising awareness of stroke risk factors with school children in Brazil, working collaboratively to identify stroke research priorities in the UK, and delivering community rehabilitation in Nigeria, we commend all the work of stroke support organizations across the globe.

WSO will continue to focus on growing, strengthening, and supporting the global stroke support organization network, particularly in low and middle-income countries, and championing the voice of stroke survivors. We know from the 2020 Global Mapping Report that despite the contribution stroke support organizations make, they face significant challenges. Lack of sustainability of financial and human resources, inadequate national stroke policies and limited data on stroke incidence and prevalence all impact the potential of stroke support organizations.

WSO wants to harness the potential of stroke support organizations to fulfil their collaborative role in stroke prevention as set out in the WSO Declaration on Global Prevention of Stroke and Dementia. We also want to see stroke support organizations empowered so they can continue to contribute to achieving the World Health Organization Global Action Plan on Non-Communicable Diseases.

We welcome this update to the Stroke Support Organization Toolkit. This is a valuable resource for organizations around the world, highlighting the core aspects of building and growing non-governmental organizations and sharing case studies from different contexts. This toolkit is a key document in our stroke support organization development programme which will guide a suite of topic manuals and supplementary activities including webinars and congress sessions.

We hope you find it useful in your important work to build your organization and to continue to contribute to addressing the global stroke burden.



A handwritten signature in black ink that reads "Shelia Martins".

Shelia Martins  
President  
World Stroke Organization



A handwritten signature in black ink that reads "Michelle Nelson".

Michelle Nelson  
Vice President  
Stroke Support Organizations  
World Stroke Organization

# 1. Introduction

Stroke support organizations (SSOs) are non-governmental organizations (NGOs) working to reduce the negative impact of stroke on individuals, their families and wider society. They are run by a mixture of people with a professional or personal interest in stroke. SSOs have unique insights into the lived experience of stroke survivors, their families, and caregivers. This enables them to deliver a range of targeted and contextually relevant activities in stroke prevention, treatment and continuity of care. These activities may include campaigning to raise awareness of stroke, providing life after stroke services, advocating for improvements in policy, and funding research into issues of importance to stroke survivors.

## Stroke Support Groups vs Registered Stroke Support Organizations (SSOs)

Although stroke support groups and SSOs both provide support to stroke survivors, stroke support groups are generally informal, whereas SSOs are legally registered organizations.

Stroke support groups may be held in hospitals or in the community. These groups are often run by volunteers who are stroke survivors, family members or care givers. The focus and activities of the group are decided by members. Some groups are for people with aphasia, younger people or caregivers. Some SSOs may have a network of stroke support groups (Stroke Association UK, March of Dimes Canada).

SSOs are non-governmental organizations (NGOs) that work towards better outcomes in stroke prevention, treatment, and continuity of care. They ensure the meaningful engagement of people affected by stroke in advocacy, fundraising, service development and research. Legal registration enables these organizations to apply for funding from governments and corporations and to partner in advocacy initiatives.

## 1.1 Stroke is a global priority

Stroke is a leading global health problem that needs to be prioritised in national health agendas worldwide<sup>1,2</sup>:

- Stroke is the **second leading cause of death**, the third leading cause of disability, and a **leading cause of dementia** worldwide.
- Global stroke mortality is predicted to rise by **50% by 2050**.
- Globally, **one in four people** over 25 years old **will have a stroke in their lifetime**.
- Each year, over **12 million people** suffer from stroke worldwide, **6.5 million people** will die and over **100 million people** in the world today have experienced a stroke.
- Stroke incidence is **increasing in young and middle-aged people** below 55 years old.
- More than **86% of the stroke burden** is experienced in **low and middle-income countries** (LMICs).

1. Feigin et al., (2022) World Stroke Organization (WSO): Global Stroke Fact Sheet 2022 Int J Stroke. 2022;17(1).

2. Feigin et al., (2023) Pragmatic solutions to reduce the global burden of stroke: a World Stroke Organization–Lancet Neurology Commission, The Lancet Neurology.

- The total cost of stroke is predicted to **rise from US\$891 billion per year** in 2017 to as much as **\$2.31 trillion by 2050**.
- Up to **90% of strokes are preventable**, by addressing a small number of risk factors, including hypertension, diet, smoking and lack of exercise.

## 1.2 WSO advocacy priorities

For the WSO's vision **A life free of stroke** to be achieved, there is more to be done. WSO has identified five advocacy priorities to reduce the global burden of stroke<sup>3</sup>:



### 1. PREVENTION

Implementation of population-wide prevention strategies.



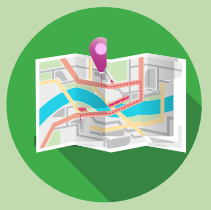
### 2. RECOGNITION

Better knowledge on risk and symptoms of stroke, and benefits of timely hospital admission.



### 3. STROKE SERVICES

Enhanced services for stroke patients.



### 4. LIFE AFTER STROKE

Improved long-term support for patients and carers after stroke.



### 5. ACTION & ACCOUNTABILITY

Development and delivery of comprehensive stroke action plans by governments.

3. A Life Free from Stroke - World Stroke Organization's Global Policy Agenda <https://www.world-stroke.org/what-we-do/awareness-advocacy/key-advocacy-priorities>

### 1.3 Growing a global SSO Network

WSO recognises the importance of SSOs and their contribution to raising awareness and improving stroke care. In 2020 WSO completed the first ever [global mapping of SSOs](#) to understand where they are located and what activities they are delivering. The responses from 92 SSOs across 58 countries showed that, not only is the global SSO network growing, and mobilizing large numbers of people affected by and engaged with stroke, but many SSOs are operating beyond their own borders. As a result, SSOs have considerable potential to drive improved stroke outcomes globally.

However, the global mapping highlighted several challenges faced by SSOs:

- The unsustainability of human and financial resources.
- Inadequate national strategies and policies for stroke prevention, treatment and recovery.
- Lack of data and awareness about stroke incidence, prevalence, symptoms, and emergency response.
- Inadequate recognition of rehabilitation in countries and limited life after stroke services.

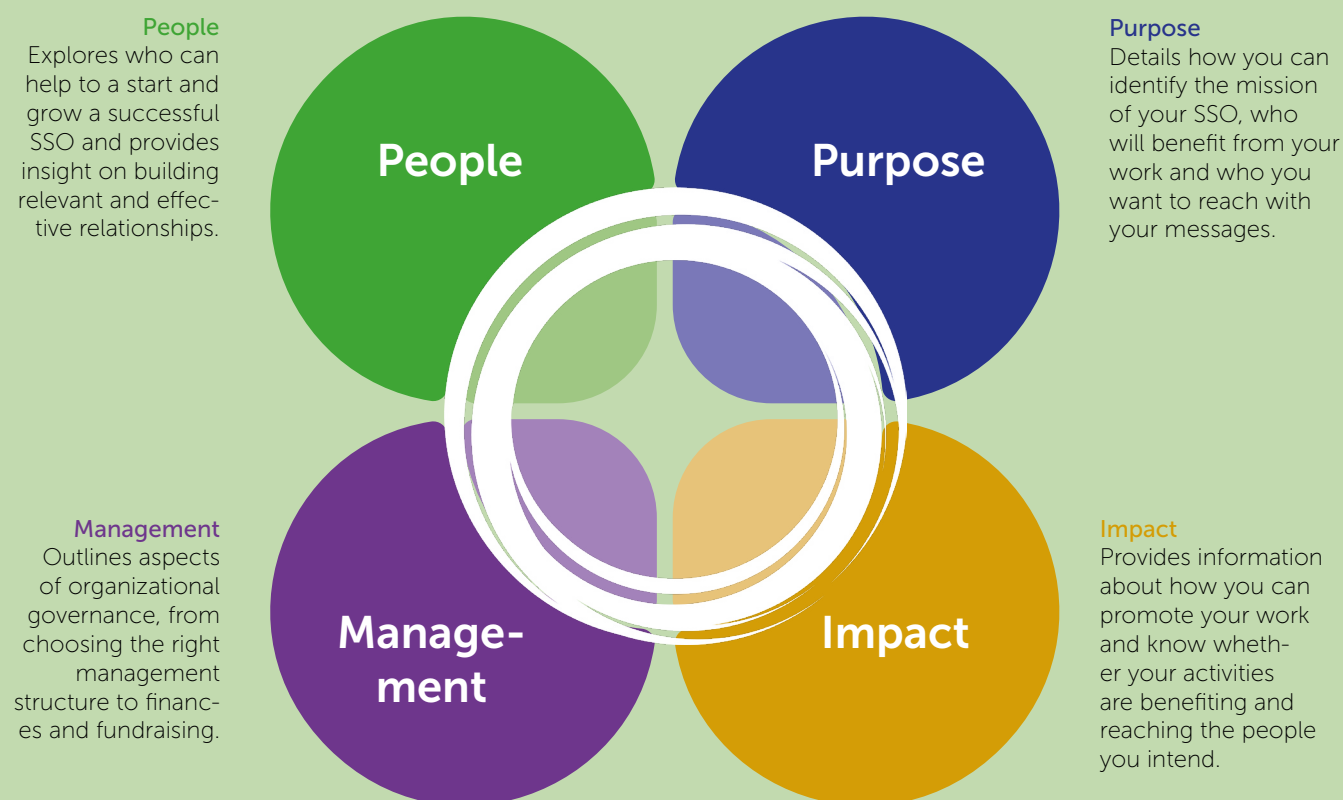
This toolkit aims to respond to some of these challenges by acting as a resource for both existing and new SSOs.

Image: National Stroke Association of Malaysia



## 2. Structure of the toolkit

The SSO Toolkit has been updated in response to a survey and research conducted with our SSO members. This toolkit is the 'core' resource offering guidance on developing and growing an SSO. It is intended to support key aspects of developing an organization: people, purpose, management and impact<sup>4</sup>. We intend to follow this core resource with a suite of manuals that will delve deeper into topics including campaigning and advocacy and life after stroke issues.



These sections are ordered in a way that should make sense for those starting out their journey to establish an SSO. However, we recognize that you may already operate an SSO or have a good idea of your mission (**Purpose**) before you start finding people to work with (**People**). We encourage readers to use the toolkit in a way that works for you and have provided pointers where there is similar content to consider in a different section. The toolkit is not intended to cover everything, but rather offer insights into key aspects of organizational development and link you to other useful resources.

SSOs and people with lived experience of stroke helped to develop this toolkit. As suggested by our survey and discussion group participants, we have provided case studies, included templates and links for further resources and kept the toolkit relatively short.

4. Adapted from Gripper, R. and Joy, I (2016) What makes a good charity: NPC's guide to charity analysis, New Philanthropy Capital.



## 3. People

Once stroke survivors, families and health professionals connect, their combined experience can contribute to establishing and growing an SSO. Although some SSOs are large, established organizations with many staff and volunteers, they share an attribute with smaller and emerging SSOs – they started from a group of people who were inspired by a common cause.

You may want to start by setting up a stroke support group, which in turn may develop into a more formal, registered organization. The pace you move at and the group or organization you establish is your choice and guided by what is needed and what works in your location.

### 3.1 Finding people

Whether you are an individual stroke survivor, family member or health professional wanting to start a registered SSO or an SSO keen to grow your existing relationships, you need to find people who have *experience, information or opportunities*. Here are some suggestions:

- **Stroke survivors, family, carers and existing support groups** have *experience* of services and support, what is working and where the gaps are. Ensure you engage people with lived experience from the start.
- **Health professionals, local hospitals and healthcare providers** have *information* about services in your location. There may be an *opportunity* for them to volunteer with you and share their professional *experience*. There may also be an *opportunity* for them to promote your activities to stroke survivors in the future.
- **Universities and academics** may have an *opportunity* for stroke survivors to join a public and patient group for a stroke research project. This group may develop into a stroke support group or SSO in the future.
- **Allied health professional students** may have the *opportunity* to volunteer their time and can support you in planning and delivering activities as part of a study placement.
- **Organizations dealing with other health conditions** may have *information* and *experience* to share or there may be the *opportunity* to work together on an activity.
- **A local or national government health bureau** may have *opportunities* for your SSO to deliver life after stroke services or be able to offer *information* on funding.
- **NGO resource centres** that offer *information* and guidance to NGOs. They may also have *opportunities* for training and funding.
- **Businesses** who complement your mission such as health equipment manufacturers, leisure facilities or food companies may have an *opportunity* for a partnership.

*“As a nurse and a physiotherapist, we saw the increasing burden of stroke in Malawi and the need to raise awareness and provide long term support in the community. We did not know each other previously but once we were connected, we soon realised that we would be more impactful in our aim to set up a stroke support organization if we worked together.”*

Emmie Malewezi &  
George Chimatiro  
co-founders  
SSO (Malawi)



As well as all the people that can help you, keep in mind that there may be others that do not want to collaborate initially. For example, existing organizations may feel that you are duplicating their work and competing for funds, or you might need to raise awareness with policy makers who think an SSO is not needed.

CASE STUDY

## Finding people: Stroke Association Sierra Leone



Stroke Association Sierra Leone is an example of an SSO that grew out of a research partnership. Stroke in Sierra Leone (SISLE) was a research collaboration between the University of Sierra Leone, King's College London, and two other British institutions<sup>5</sup>. SISLE empowered stroke survivors and caregivers to have direct involvement in and co-produce aspects of the research, and these local participants went on to establish the Stroke Association of Sierra Leone, which was legally registered as an NGO in 2021.

Co-founders James Williams and Daniel James say that the SISLE project inspired them to formalize the group created during the research. They knew from their own experience that there was little knowledge about stroke in the community. The association started a campaign of stroke awareness through radio, newspaper, and TV. The association has begun to challenge views that stroke is a death sentence, and that it is caused by sex or witchcraft. Stroke Association Sierra Leone continues monthly meetings of stroke survivors and carers as vital support for life after stroke.

The founders identified the need for an SSO beyond the initial research collaboration. Two years on, Stroke Association Sierra Leone has a membership of 90 stroke survivors and carers and has started to establish relationships with the Ministry of Health.



### Templates and resources

- Grassroots Collective has an excellent [module on project planning](#) which includes templates and resources you can use for stakeholder analysis.
- Connecting Evidence provides a clear explanation of how to carry out stakeholder mapping in this [YouTube video](#).
- This [Stakeholder Engagement Plan Template](#) created by Sustainability Victoria is another tool you can use to identify what you will say to stakeholders, what level of input you would like from them, and what channels you will use.



### Take away

**Remember, it is always important to spend time networking, building relationships and earning trust to achieve your aims. Think about what experience, information and opportunities people can offer as you establish and grow your SSO.**

5. Led by Professor Catherine Sackley, SISLE was a collaboration between King's, University of Glasgow, University of Central Lancashire, Guy's and St Thomas' NHS Foundation Trust, and the College of Medicine and Allied Health Sciences in Sierra Leone. See more at <https://www.kcl.ac.uk/research/stroke>.

## 3.2 Working with volunteers

Working with volunteers to raise funds and deliver activities is very important. You will need to think about **what** activities you would like volunteers to do, **where** you recruit volunteers and **how** you manage them.

- **What?** Start by developing a list of activities volunteers can do. Then create role descriptions so everyone is clear about the volunteer activities. There may be times in the year when you need volunteers much more, such as World Stroke Day. You can attract new volunteers by highlighting the work of your existing volunteers in your social media to show how much you appreciate and value them and the kind of work they do for your SSO.
- **Where?** Advertise volunteering opportunities using the role descriptions in as many places as possible to increase the diversity and number of new volunteers. Use volunteer agencies, online recruitment, partnerships with health professionals, universities, and other NGOs. Promote a variety of roles to attract different skills, experience and ages. For more technical roles you may look for a volunteer who has specific skills or has carried out the role before.
- **How?** Supporting volunteers is very important. Keep in mind that volunteers with lived experience of stroke may need different kinds of support. Take the time to ask and allow them to guide you on the kind of support they need to fulfil their role. Volunteers should have access to training, time to talk with each other, recognition of their contribution, information on safety, whether they can claim expenses and how to raise any concerns.

### CASE STUDY

## Working with volunteers: National Stroke Association of Malaysia



The seed for the National Stroke Association of Malaysia (NASAM) was sown in 1995, when stroke survivor Janet Yeo's story of recovery appeared in a newspaper. This prompted an avalanche of responses from the public and resulted in the formation of a stroke support group. The group initially met for talks from healthcare professionals but as word spread, many called for the development of services for stroke survivors.

NASAM's first physiotherapist Doreen Tan recalls: "The numbers grew very quickly, and our daily two-hour sessions crept from the porch into Janet's house. Not long after, we realised we needed extra hands and that's when volunteers first came to our rescue." One of NASAM's other pioneering members, Kamsiah Bostock, initiated volunteer training which is still ongoing. Today NASAM carries out its work through eight stroke centres across Malaysia. These centres provide affordable stroke specific rehabilitation from Monday to Friday, which would not be possible without the help of volunteers. Volunteers are trained to help stroke survivors with their rehabilitation, and to counsel families facing the increased responsibility of caring for a stroke survivor.

NASAM's remarkable resilience highlights the need for extensive support networks, from healthcare professionals to business communities and ordinary people in the community. "No qualifications are required," says NASAM's volunteer recruitment request, "just a lively, warm-hearted attitude, some time to spare and your desire to help."



## Templates and resources

- Volunteer Checklist:

1	Identify ways in which volunteers could be beneficial to your SSO.	
2	Using this information, create a plan that includes how you will recruit volunteers, what roles they will fulfil and how they will be managed.	
3	Create any documents you need such as recruitment forms, job descriptions, feedback forms, advertisements, expenses forms, etc.	
4	Advertise volunteer roles in relevant spaces – use your existing network to spread opportunities via word of mouth, print or online advertising.	
5	If you need someone with a particular skill, reach out to people in that industry to ask for help and/or ask similar organizations for recommendations.	
6	Check in with your volunteers on a regular basis and create a mechanism for feedback, review, and implementing changes.	
7	Support your volunteers with necessary training and a variety of opportunities to ensure they remain interested and engaged.	
8	Create a culture that rewards volunteer commitment – thank your volunteers publicly and celebrate their successes.	

- MS Word/Excel offer a variety of useful templates. Open 'New Document from Template' and search the word 'Volunteer' to find what's on offer.
- Volunteering Resource Hub of Volunteering Australia, has free and downloadable [Guides and Templates](#) from voluntary organizations in Australia and worldwide. Includes a Framework for your Volunteer Policy and a Volunteer Certificate of Appreciation.
- Here are some example Job and Volunteer advertisements and descriptions:
  - Stroke Association UK [Volunteer Role Description Example](#)
  - Stroke Foundation Australia [Volunteer Advertisement Example](#)



## Take away

Stroke survivors, families and carers can be important volunteers for your SSO. Their story can be very powerful in attracting donors and influencing policy and decision-makers. If you give clarity on roles, ongoing support and recognition then volunteers are more likely to remain committed. Think about creating a forum for your volunteers, regular training events, volunteer awards ceremonies, and volunteer stories in your newsletter.

### 3.3 Building relationships

In section 3.1 and 3.2 we looked at the people you could reach out to and how to manage people who volunteer for your SSO. In this section we look a little deeper into how you can build relationships with different people who may support your SSO, benefit from your SSO or who you may need to influence. Strong relationships with a range of collaborators can help your SSO make a difference in stroke prevention, treatment and continuity of care.

#### People with lived experience of stroke and other non-communicable diseases (NCDs)

Stroke survivors, carers, and family members are arguably the most important relationships to develop. This is because they offer unique, invaluable insights about the experience of stroke, and treatment and recovery that can direct your SSO's purpose and activities. There are many opportunities to involve people with lived experience of stroke in your SSO:

- **Participation** – in newsletters, focus groups, panel discussions, and surveys.
- **Collaboration** – through campaign committees, advisory or reference groups.
- **Co-production** – representation in your SSO's decision-making and co-producing activities and publications<sup>6</sup>

#### Policymakers

NGOs play an important role as advocates who can influence decisions and policies of governments. Advocacy can be achieved by influencing public opinion, but it is also carried out through direct relationships with policymakers. Building relationships with policymakers is crucial to ensuring your purpose is carried out effectively and your voice is heard. Here are some ideas to help you build relationships with policy makers:

- **Establish direct communication** by identifying relevant government officials and decision-makers connected to stroke. Reach out through emails, phone calls and face-to-face meetings. Invite them to events and involve them in your work, so that they become personally invested.
- **Attend public meetings and events** that the policymakers will be present at. Use any opportunity – such as question time or networking breaks – to interact with and inform policymakers about your SSO's work.
- **Utilize social media** as an engagement tool to raise awareness about your SSO's activities and successes. Tag or respond to posts about specific policies.
- **Be clear and concise** when you are communicating with policymakers. Be clear about what you are going to say about your purpose, activities and impact and be prepared to answer questions in a concise way.
- **Bring your unique, invaluable insights** about the lived experience of stroke, treatment and recovery to the attention of policy makers.
- **Be persistent** and recognize that engaging policymakers is an ongoing process.
- **Make sure you remain informed** about relevant policies and changes that will affect your SSO's beneficiaries.

6. Adapted from NCD Alliance. Meaningfully Involving People Living with NCDs: What is being done and why it matters. [https://ncdalliance.org/sites/default/files/resource\\_files/MeaningfullyInvolvingPLWNCDs\\_Report\\_FINAL.pdf](https://ncdalliance.org/sites/default/files/resource_files/MeaningfullyInvolvingPLWNCDs_Report_FINAL.pdf)

## Health Professionals

Stroke is a multidisciplinary specialty, so stroke health professionals come from different medical backgrounds and from multiple settings within the stroke care pathway. Accordingly, they can offer different levels and areas of expertise to your SSO.

- **Identify the different health professionals** your SSO interacts with, or intends to work with, and on which specific projects or activities. This will allow you to create an engagement plan that can be regularly updated.
- **Use your existing network to find relevant health professionals.** Your SSO may have been established by clinicians or you may need to approach doctors and therapists who helped you during your own stroke journey.
- **Make sure roles are clearly defined from the outset,** so that expectations can be managed on both sides. Health professionals may have certain knowledge and be familiar with systems and ways of doing things that are completely different to your SSO.

## Researchers

Research is crucial to improving stroke prevention, treatment and recovery. Your SSO is uniquely placed to provide stroke researchers with information about and access to people with lived experience of stroke. As you develop your SSO's relationship with academia, here are some questions to consider:

- **Research focus.** Is there a particular stroke issue in your context that you are concerned with? Or a beneficiary demographic you would like to impact? Do you have members with specific stroke interests? For example, how stroke affects young people?
- **Engagement with stroke researchers.** Would you like them to be members of your management committee? Or are you interested in partnering for specific research projects and facilitating the involvement of people with lived experience?
- **Funding research.** Do you have access to a donor that may be interested in funding research? Or could you raise funds for research from the general public?

Image: Spot Stroke Fast Foundation, Ghana



## CASE STUDY

# Building Relationships: The Heart and Stroke Foundation of Barbados



The Heart and Stroke Foundation of Barbados works in collaboration with the public health care system to ensure people who have a stroke have early access to rehabilitation in the community. The situation in Barbados is all too familiar: an over-stretched and over-worked public health care system that is not always able to provide the optimal amount of rehabilitation for people that have experienced a stroke.

Heart and Stroke Foundation of Barbados has therefore prioritised its rehabilitation programme to meet the needs of stroke survivors and to work alongside the public health care system. The foundation has a specific arrangement with the Ministry of Health and Wellness to facilitate enrolment in the rehabilitation programme and receives referrals from the Queen Elizabeth Hospital. The foundation collaborates with consultants and professional volunteers to adequately deliver the necessary elements for this rehabilitation programme. However, there is still a need for greater collaboration because of the high demand for services within the community.

Stroke survivors meet twice a week and activities are planned and guided by the occupational therapist and the rehabilitation therapy technician. Within the programme, the Heart and Stroke Foundation of Barbados also facilitates a support group to respond to the psychosocial needs of stroke survivors. The support group has helped stroke survivors cope and adapt to the effects of their stroke and find hope for the future.



## Templates and resources

- A [detailed guide](#) to fostering donor relationships by Donorbox
- Creating a Pitch Deck to tell your SSO's story: Funds for NGOs [guide](#), Canva [Webinar](#)
- LinkedIn provides a series of articles powered by AI and members' contributions around [Community Organizing](#) and [Community Outreach](#) that may provide some useful insights to your SSO
- Stroke Foundation Australia [framework](#) for academics interested in Research Partnerships is a resource to help you consider how your SSO can engage researchers



## Take away

- **Start Small, build buy-in, show results – it takes time to establish trust and build strong connections.**
- **Create mutual benefit – the relationship should benefit both sides. Make sure you maintain flexibility and allow learning and understanding to grow.**
- **Create a culture of involvement – that encourages and supports everyone to think critically, take risks with new ideas, allow for mistakes and value people's contributions.**



# 4. Purpose

People and purpose are closely connected. Your purpose is the reason your SSO exists. In most cases, SSOs grow out of the stroke experience of their founders and members, whether lived experience or professional experience. Consequently, the SSO's purpose will be driven by the specific challenges or needs at both an individual and health system level. An organization's purpose is often referred to as its 'mission'.

## 4.1 What is the need?

The starting point is to understand the current situation or context of stroke awareness, prevention, or care in your country and what the gaps are. You can then explore what your SSO can do to address these gaps. Contextual factors to consider include:

### The healthcare system in your country

- A free government system – however, there may still be a need for your SSO to provide such things as emotional support and guidance on benefits for stroke survivors.
- A mainly free system with some contribution by individuals/employers – there may be a need for your SSO to advise on what healthcare costs for stroke are covered.
- Costs are largely or fully covered by personal or employment contributed insurance and those without insurance pay for their own health care – your SSO may need to advise on where to find affordable therapy or there may be an opportunity for your SSO to collaborate with professional therapists to provide rehabilitation activities.

### The NGO landscape in your country

- Are there other NGOs working on NCDs? Could your SSO's purpose be something that they are not currently addressing?
- If NGOs are not usually funded in your country, where else might you access funding?
- Are NGOs able to campaign and advocate in your country? Are there any restrictions that you will have to consider when identifying your purpose?

### Existing knowledge and attitudes about stroke in your country

- In the SSO mapping, we found just over two-thirds of SSOs reported that 'inadequate policies for stroke prevention' affected their delivery of awareness campaigns. This kind of stroke 'invisibility' within national policy is challenging, but it may help you identify the specific need for policy influencing in your country.
- The findings of a 2022 Gallup survey show that globally there is a disparity between public perception and the actual burden of stroke, particularly in LMICs and among individuals with lower education levels. There is also a general misunderstanding that stroke is not preventable<sup>7</sup>. If there is poor public perception of stroke in your country, this may be a need that your SSO can help to address.

### Specific groups

- By taking time to understand the needs of certain groups or priority risk factors in your country, then you can target your activities and this is likely to have greater impact. Some examples are:

7. <https://www.world-stroke.org/news-and-blog/news/addressing-the-stroke-perception-gap>

- Targeted awareness raising by Associação AÇÃO AVC Brazil with school children in [a project](#) with the Municipal School that combined maths and statistics with stroke information.
- Encouraging active participation of women by the Bindu Menon Foundation India in the [EDuWAND project](#) to address the burden of stroke for women.

CASE STUDY

## What is your Purpose? Coming Home Organization, South Africa



Avashna Moodley calls herself a 'stroke veteran' because she faced 'long service' in her recovery and over 11 years on, still carries the scars. She was an ambitious, busy 41-year-old entrepreneur when she suffered a stroke that left her physically incapacitated. "There were no warning signs, no time to get my affairs in order, to prepare my kids for their mother who could no longer walk, talk, read, write or recall her life," she says.

Avashna's stroke stripped her of everything. She describes being left in the shade of a tree, under which she had not planned to sit. It took many years, but Avashna learnt to rebuild her life layer by layer. The experience showed her that recovery from any life-threatening condition cannot be done alone, and revealed to her the gap in care once patients left the hospital. This insight was the catalyst in setting up Coming Home, an SSO that offers home-based care and support to anyone affected by chronic illness in her community just north of Durban, in South Africa.

Coming Home's purpose is clear – to provide a customized support programme to ensure rapid recovery in the comfort of the patient's own home.



### Templates and resources

- [PESTLE Analysis Template](#) from Charity Commission for England and Wales may help when assessing the risk arising from external factors. And [further explanation](#) by Scribd of how to use PESTLE for NGO strategic planning.
- The World Stroke Organization [Global Stroke Guidelines](#) could help with your analysis of the status of stroke care services in your country.
- Examples of SSO mission statements:
  - **Heart and Stroke Foundation of Barbados:** To reduce suffering and death from heart disease and stroke.
  - **Associação AÇÃO AVC Brazil:** To share knowledge about stroke, to inspire hope and new possibilities for those affected by stroke.
- To help write your mission statement [Donorbox Guide](#) to writing a mission statement includes a free worksheet and examples.
- There may be data from your country or region that can tell you about priority needs in stroke care such as the [Burden of Stroke in Europe Report](#) and the [Global, Regional, and National Burden of Stroke](#) systematic analysis





## Take away

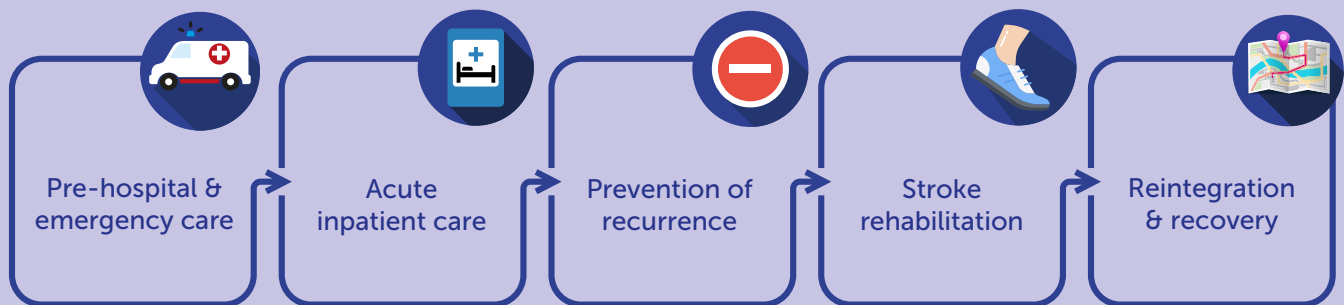
Your SSO's purpose, is the reason your SSO exists, and is informed by specific needs in your national context. The purpose can be presented as a 'mission statement'. Take time to understand your context so that you can be confident about the purpose or mission of your SSO, why it is so important and the opportunities available for you to have impact.

## 4.2 Beneficiaries and target audience

### Beneficiaries

The beneficiaries of an SSO are the reason you are doing the work in the first place. They are the people benefiting from your purpose and directly benefiting from your activities. SSOs target their activities for beneficiaries at different stages along the stroke care pathway, from prevention and treatment to rehabilitation and life after stroke. For some SSOs this may be a very specific group of people, for example, young stroke survivors or carers.

### STROKE CARE PATHWAY



Be careful not to think of your beneficiaries only as people who simply benefit from your activities. They are important participants in your SSO who can influence the purpose, management and impact of your work. Building relationships with your beneficiaries and providing them opportunities to participate in, collaborate with and co-produce your activities is a powerful way to carry out your mission.

### Target Audience

Alongside delivering services with and for stroke survivors and carers, there are many other people, from policy makers to 'at risk' groups, that might be the 'target' or focus of your activities. Your target audience is the wider group of people who can benefit from your SSO or that you are trying to influence. This could include FAST awareness for the general public, or influencing policy makers to develop a national stroke policy.

You can use various methods to identify your target audience and beneficiaries, such as stakeholder analysis, market research, surveys, interviews, focus groups, or observation.

Ultimately the 'who' in your mission statement will be determined by your individual context and experience, and the problem/s you are seeking to address.

## CASE STUDY

# Identifying your beneficiaries: Michael and Francisca Foundation Nigeria



Based in Lagos, Nigeria, the mission of the Michael and Francisca Foundation is “to create public awareness on Stroke/NCDs and to provide encouragement and support for all impacted by NCDs, giving them hope.” It’s a mission that founder and Chairman, Michael Uchunor, has personally lived. In 2012, at the relatively young age of 32, Michael was rushed to hospital unable to move or speak after experiencing a stroke.

Michael explains that once he was discharged there was no stroke support group for him to access – no opportunity to meet other stroke survivors, share stories, challenges, and inspirations, and to learn about potential treatments or new research. Michael has progressed well in his recovery since then, perhaps in part, because he invested his energies into filling the void and creating an organization that provides a place for stroke survivors and their relatives connect with one another. Stroke survivors and their relatives are the beneficiaries of the Michael and Francisca Foundation’s activities.

Michael says that there is still need for increased awareness about the causes of stroke in his community, and he is adamant that “people with lived experience have an important role to play as agents of change and empowerment.”



## Templates and resources

Refer to section 3.1 for help with stakeholder analysis and 4.1 if you need assistance determining your mission.



## Take away

**Beneficiaries are the people actually receiving benefit from what your organization does and the target audience is who you are trying to reach with your messages. Your beneficiaries and target audience should be clearly linked to your mission. Your beneficiaries don’t simply benefit from your activities. They are important people in your SSO who can influence its purpose, management and impact.**

## 4.3 Achieving your purpose

In order to address the needs you have identified in your context, the next step is to identify the activities that could be solutions to these needs. You will not be able to do everything so you will then need to prioritise or choose from these activities and then implement them.

## Identifying possible activities

- **Will you run peer support groups?** Your SSO could facilitate peer support groups by organising the location for them to take place, providing refreshments, and helping to run events and trips. Here is an example of Stroke Association UK's [Stroke Support Groups](#).
- **Will you offer a telephone or online help service?** You could offer a telephone or online help service so that people affected by stroke can contact you from wherever they live in your country. You will need to consider the kind of support you can offer and whether you will have health professionals involved. Stroke Foundation Australia runs a [StrokeLine](#) providing practical, free and confidential advice.
- **Will you develop information about stroke?** You can create information leaflets and on-line content for stroke survivors, their families and carers. Associação Brasil AVC [develops informative materials](#) with the help of volunteer health professionals which can be used by stroke survivors, health professionals and students. You could consider agreeing with hospitals to have your information available for patients when they leave hospital.
- **Will you visit people in hospital or run a befriending programme?** Organising volunteers to visit people in hospital and to connect with stroke survivors and their families when they leave hospital can be a lifeline for many people, especially in the early weeks and months. The Singapore National Stroke Association has created [two support networks](#), one for stroke survivors and one for caregivers.
- **Will you deliver training?** Consider who will want or need training in stroke – your staff and volunteers, other NGOs, the general public, stroke survivors and carers, professionals or students. The people delivering the training may need to be registered professionals. During the COVID pandemic, Heart and Stroke Foundation Canada developed a [series of webinars](#) for stroke survivors and carers.

Image: Stroke Foundation, Australia



- **Will you campaign and try to influence policy?** Many SSOs play an important role in campaigning to raise awareness of stroke and try to influence policy to improve stroke prevention, treatment and care. The meaningful involvement of people with lived experience of stroke is very important and powerful in campaigning. Your SSO will need to understand the current gaps in stroke policy and services. In 2021, Stroke Action Rwanda [took the lead in marking World Stroke Day](#) for the first time in the country. The event prompted the Ministry of Health to publicly express concern and call for a robust national awareness campaign on stroke.

## Your strategy

There are lots of activities you could deliver to achieve your purpose. However, you will not be able to do everything. Developing your SSO's strategy is sometimes described as a roadmap, in which you detail where you are aiming to get to and why. You identify the priority activities that need to happen to get you to your destination, what resources you will need and any challenges you may face. Some of the things to include in a strategy are:

- The **current situation** or context of stroke awareness, prevention, or care in your country and what the gaps are (see Section 4.1).
- Your **mission statement** that sets out your role to address specific gaps in stroke care (see Section 4.1).
- Your **priority activities** that will enable you to deliver your mission. To help identify your priority activities think about:
  - The **impact** the activity could have on the people you want to help. Do you know if this activity is important to stroke survivors?
  - How much **resource** will be needed for the activity? Do you have what you need to do the activity? Consider resources such as money, people and their time, materials, premises and computer equipment.
  - The **pace** you can carry it out. How soon do you need to do the activity? Is there an event you need to be involved with or respond to, such as drafting a stroke policy?
- How high or low the **risks** are. Are there any risks to your SSO's reputation, finances or the safety of your staff and volunteers?

## Implementing activities

To deliver your strategy, it is important to develop a plan of your activities – this is sometimes called an operational or implementation plan. This plan includes activity details of why, what, how, when and who. The plan will help you to check if the activity is happening, that it is happening on time and at the right cost and who is involved in making it happen. It can also help you to see if there are any problems.

- **Why, what, how, when, who**  
**Why** The reason or objective for the activity – for example, improving awareness of stroke.  
**What** Stroke information leaflets  
**How** Publication of stroke information for the public on your website.  
**When** A new publication every three months this year.  
**Who** A named volunteer working in collaboration with a volunteer health professional.
- **Realistic plan** Ensure that your plan is based on the time required to complete the activity and the budget that you have available. Particularly, in a volunteer-based organization, it is easy to be optimistic about how much time someone has got and how long it could take to complete certain tasks.

- **Review the plan** Make sure that you can report every six months on how your SSO is performing against the what, how and when.
- **Be focused but flexible** Focus on doing the important things well and don't be afraid to change things.



## Prioritising activities: Stroke Support Organization, Malawi



With stroke the sixth leading cause of death and a significant cause of disability in Malawi, increasing stroke knowledge about risk factors is a priority for SSO (Malawi). For May Stroke Awareness Month in 2022, SSO (Malawi) lined up an ambitious awareness programme, which it had no hope of funding independently. Instead, the SSO built relationships with health-conscious corporations, including Telecommunication Malawi Limited and NBS Bank. They adopted an innovative win-win approach; and developed a plan to offer awareness activities that targeted the companies' young corporate workforces while simultaneously securing funding from the companies.

With the funding SSO (Malawi) was able to finance the translation, printing, and dissemination of stroke awareness materials in the local language, Chichewa. They also developed stroke awareness jingles for radio and TV and carried out "Know Your Blood Pressure" campaigns with donated blood pressure machines from another corporation, Moto Money.

SSO (Malawi) is clear that prioritising stroke awareness for working age people led to a win-win approach that enabled corporate buy in. The offer of stroke information was appealing to the corporations, who had a vested interest in managing the stroke risk factors of their employees. SSO (Malawi) was also flexible and adapted their programme to the requests of the corporations, for example delivering separate sessions for employees and managers.



### Templates and resources

- Intrac [Toolkit for small NGOs](#) – accessible online or with downloadable PDF. Includes templates.
- Civicus [Strategic Planning Toolkit](#) – MS Word
- Tools4dev free downloadable [Strategic Plan Template](#) – MS Word



### Take away

Planning is the process of defining where an organization is going and how it will meet its objectives. It requires you to identify relevant activities to meet the needs identified, prioritise them and then implement them according to a plan.



# 5. Management

## 5.1 Organizational governance and registration

### Governance

Every organization, regardless of size or purpose, needs to decide on a management structure. This is the way you organize your resources – people and financial, to enable you to deliver your purpose and activities. If you are a small stroke support group and you are not registered, you may simply want to assign individual roles and responsibilities on a voluntary basis. However, if you are a formal SSO that is registered, there will be legal requirements. Below are some examples of possible organizational governance structures:

- **A decision-making board** which is elected from existing staff or volunteers.
- **A CEO or president** who is supported by a group of directors or managers and reports to a Board of Trustees.
- **National or regional committees** with representatives voted into decision-making positions.

### Registration

Whether you need to register your SSO will depend on your activities and the pace at which you grow and develop. If you are employing staff and raising funds, then it is likely that national laws will require your SSO to register as a legal entity. Here are some advantages of operating as a registered NGO:

- **Legal recognition** and can enter into its own contracts and administrative arrangements. This removes the risk of personal liability for any member of your SSO.
- **Charity status** with the tax department that allows for tax concessions for donors and for the organization itself, and sometimes even exempts the organization from certain laws.
- **Eligible for funding and grants** that private companies cannot apply for, especially in relation to government funding.
- **Credibility** to your work that you can't get as a private individual. This is often helpful when trying to attract donor funding.



### Templates and resources

Community organization toolboxes:

- Community Door's [resource bank](#) of management policies, procedures and templates designed to help with the day-to-day running of a community organisation.
- Education and Training Unit South Africa has this [Community Organisers Toolbox](#). Some of the information is specific to the South African context but most of it is applicable anywhere or can be used as a sample.

Constitution Samples and Guides:

- The Resource Centre UK has this [step-by-step guide](#) to writing a constitution for a small community group, with a sample included.
- The Charity Commission UK has this [sample Small Charity Constitution](#)



## Take away

Remember, depending on where you are in the world, there may be different options for registration and requirements for governing documents. If you are unsure what the situation is in your country, you can ask existing community groups, do some of your own internet research or enquire with a law firm that does company registrations.

## 5.2 Managing finances

No matter the official structure of your SSO, you will be receiving and spending money to achieve your purpose. Effective financial management requires that you are transparent with your finances. Here are some financial best practices that will ensure you maintain a good financial reputation and meet your goals<sup>8</sup>:

- **An accounting system** Whether your transactions are cash-based, or you operate a bank account, you will need to have a system to record and keep track of your accounts. Once your SSO starts attracting larger amounts of funding, employing a book keeper and accountant is advised so that you can be confident in your SSO's financial management and compliance.
- **A budget** A budget should include your best estimate of income and expenditure for any activities that you want to undertake. Make sure you are realistic, and if needs be, create smaller budgets for shorter time periods before embarking on something like an annual budget. Your budget should be developed alongside your plan.
- **Policies and Procedures** This can include things like how you will reimburse expenses, what kind of gifts you can receive, what kind of reporting you need to do and when, a code of conduct and conflict of interest policy.



## Templates and resources

- Here is a [budget template](#) from Tools4Dev
- Wallace Foundation [Toolkit](#) on Budgeting
- Non-profit Finance Fund's Fundamentals for Non-profits [Finance Resources](#)
- Propel Non-profits [Resources](#) on Fiscal, Board/Governance



## Take away

No matter what level of funding your SSO receives, you need to ensure that you spend it the way that you told donors you would and you need to be able to account for it. Everyone in the SSO has a role to play in financial management, from volunteers following the procedures correctly to claim expenses, to the book keeper ensuring the records are up to date.

8. [Further detail can be found at https://www.jitasagroup.com/jitasa\\_nonprofit\\_blog/non-profit-financial-management/](https://www.jitasagroup.com/jitasa_nonprofit_blog/non-profit-financial-management/)

## 5.3 Fundraising

One of the first major decisions to seriously consider when setting up an SSO is where you are going to get the funding to start and run your organization. In the global SSO mapping, we found that the biggest barrier to starting or growing an SSO is financial support. Funding sources to consider throughout your SSO's journey include:

- **People with an interest in your work** Start with your existing network - people you, your volunteers, partners, and contacts know.
- **Trusts and Foundations** There are donor organizations that exist to provide funding for NGOs. Try to find, or make your own list, of relevant organizations. Take note of the kind and amounts of funding they offer and when you can apply for it.
- **Community organisations, clubs, and societies** Many sporting clubs or community clubs provide funding for good causes and may be willing to run a fundraising event for your SSO. Examples of well-known international clubs include Rotary Clubs and Lions Clubs International.
- **Companies** As part of corporate social responsibility, it is important for companies to be seen to support the communities they work in. Companies with an interest in your work may provide initial start-up funds and if you establish a good relationship, may continue to invest in your work. Make sure you have a clear agreement of when and how you will receive the funding.
- **National and local government** may provide funds or grants for health NGOs, but this kind of funding is heavily dependent on your location. Government funds may not be as readily available in LMICs as they are in places like Europe or the USA. However, it's always worth investigating government opportunities because they may have received funding from international organizations to disburse.

Image: Dr Bindu Menon Foundation, India





- **Fundraising events or campaigns** If you have a specific amount or activity you want to raise money for, advertising for donations through posters, adverts, letters, TV, and radio or online, can be a successful method. You can create a specific fundraising campaign that is promoted across several platforms.
- **Chargeable services** As well as thinking about who will give you donations or funding, think about services you can charge for. Will running events for stroke professionals or delivering services for the health authority bring you income?
- **Securing a number of 'committed givers'**. Many NGOs increase their income through regular 'committed' giving by individuals. People find it easy, convenient, and affordable since they give a small amount regularly. For SSOs it can provide a predictable annual income and increases the numbers of donors that you keep.

### Diversify your funding, and don't rely exclusively on one funding source

Relying too heavily on one source of funding can negatively affect your SSO's operations if that money suddenly becomes unavailable. Diversifying your funders will provide you with more autonomy and security as an organisation. Having multiple donors and applying for some sources of unrestricted funding that is not tied to one activity, will enable you to operate more sustainably. However, managing multiple donors requires effective financial management. Your SSO must be clear which donor is funding which activity to avoid any duplication.

#### CASE STUDY

## Diversifying funding: Stroke Action Nigeria



Rita Melifonwu, founder, and chief executive of Stroke Action, a leading SSO in Nigeria, leveraged her relationship with Philips Foundation to create a partnership opportunity for the SSO. As an Ashoka Fellow for Health, Ms Melifonwu was connected to Philips Foundation and in turn, a programme Philips supported – Collavidence (now branded as [Let's Get Proof](#)). This platform combines elements of peer review, open-source contribution, and crowdfunding, enabling innovators in medicine to find the expertise, insight, and funding they need to make their projects a reality.

In partnership with these organizations, Stroke Action Nigeria has developed the study proposal 'Determining the effectiveness of the Nigerian Life after Stroke Centre (LASC) Program'. Evidence of effectiveness of their LASC program could provide a model of care that could be replicated in other low resource settings, influence local and national policy to improve community-based stroke care, and have the potential to address a gaping hole in post-stroke care in similarly challenging environments.

Gaps in such stroke care research are exacerbated by how competitive funding streams can be, particularly in low resource settings, like Nigeria. As an SSO, it is important to consider alternative or complementary sources of funding. As Stroke Action's experience highlights, raising hybrid finance in partnerships with research funders and philanthropic organizations can be an important way to support the sustainability of SSOs.



## Templates and resources

- Develop a table of potential donors to help you get organised, rank the prospect or likelihood that you may receive funds, plan your actions to engage and apply or approach the donor:

Donor name	Website	Focus area	Prospect rank	Application information	Action
------------	---------	------------	---------------	-------------------------	--------

- Non-profit Finance Fund's [Fundraising Guide for Non-profits](#)
- National Council of Non-profits Fundraising and Resource Development [tools and resources](#)
- Intrac [Fundraising for Success](#)



## Take away

When it comes to fundraising, start small and scale up as you grow and gain more experience. The reality is that operating a successful SSO will require a balanced and sustainable funding flow, so finding people with grant writing knowledge and funding networks will help you enormously.

Image: The March of Dimes, Canada





# 6. Impact

## 6.1 Monitoring and evaluation

Monitoring and evaluation need to be included in your plans and budget. You need to monitor your progress and evaluate the impact of your activities. Unless your SSO is monitoring and evaluating its activities, it will be more difficult to:

- Stay within time and cost limits and focus on what's most important.
- Produce reports of your planned activities.
- Decide on corrective actions when things don't go as planned.
- Remain flexible to changes affecting your SSO.

### Monitoring<sup>9</sup>

Monitoring is the continuous collection of data and information as you implement your activities. This will help you to understand whether your activities are making progress towards the changes or outcomes that you planned. It helps you to understand if your activities are going according to plan and will alert you to things that may need changing.

To find out if you are making progress towards your outcomes you need to collect data about your activities. Make sure that you are keeping a record of this data. There are different types of data you can collect:



**Beneficiary data** if your activity is aiming to respond to the needs of people affected by stroke, you will need to know what their needs are. When people first come to your SSO, collect data about the specific support that they need.



**Engagement data** once the activity has started you will need to know if people are engaging with it. You can collect data about how often people come, for how long, what kinds of activities they engage in, and who does and does not engage.



**Feedback data** it is important to know not only whether people are engaging but also if they are benefiting from the activity. Collect data about what people think about the activity, whether they are enjoying it, whether they find it useful and would recommend it to another stroke survivor.



**Outcomes data** will tell you whether you are making progress towards the changes or outcomes that you planned. How have people been helped in the short-term? How do they think your service is helping? This data will be important for the evaluation at the end of the project.

### Evaluation

Evaluation takes place towards the end of a project or after the project has been completed. Evaluation looks at the changes that the activities achieved. These changes may be what you expected to happen but other changes may be unexpected. Evaluation also looks at the lessons learned, value for money, and whether the activities were the right thing to do to meet the needs you identified.

Key questions to answer in your evaluation are:

9. <https://www.ngoconnect.net/sites/default/files/resources/Monitoring%20and%20Evaluation%20CIVICUS.pdf>

- What changes or outcomes have people experienced as a result of the activity?
- How relevant or appropriate are these outcomes to the needs of the beneficiaries, do these outcomes match the overall goal of the activity?
- What data or evidence is there of the impact or longer-term change as a result of the activity?
- How sustainable are these changes? Can these changes be maintained even if the activity has ended?
- In some activities, collaboration with other organizations may also be important in evaluating the impact of the activity. How well did you collaborate with or influence other organizations? Has this helped with the sustainability of the changes?



## An approach to evaluation: Stroke Association UK



The Stroke Association UK is committed to being “Stroke to the core” and to “Know how to make an impact”. The Ask and Act evaluation approach has been developed to further both of these principles. The approach is being co-created with beneficiaries, staff and volunteers, and is being rolled out across all of Stroke Association’s work with beneficiaries. The Stroke Association is aiming to focus on the difference they make, rather than the work that they do.

The Stroke Association has worked to co-create measures with people affected by stroke in line with the following principles: focusing on experiences and outcomes, using beneficiary voices, person centred, empowering learning and action.

Many SSOs are delivering services in the community for people affected by stroke and they all need to be intentional about understanding whether these services are meeting the expressed needs of beneficiaries. This approach has the potential to enable SSO staff and volunteers to learn from beneficiary feedback and identify future priorities together. Ask and Act aims to be empowering for beneficiaries - enabling them to tell their story, and at a time and in a way that suits them.



### Templates and resources

- Tools4dev How to write a Monitoring and Evaluation Framework [guide and templates](#)
- Grassroots Collective Grassroots Hub [resource library and online courses](#) including Tools for Project Planning
- Global Giving Social Impact [Terminology Definitions](#)
- Better Evaluation [Online Evaluation Platform](#)
- Imagine Canada [Project Evaluation Guide](#)



## Take away

Monitoring and evaluation are important for learning. Learning is about what has worked well and also what has worked less well. Decide on the data you need to collect that will tell you whether your activities are making a difference.

## 6.2 Media and Promotion

### Beneficiaries

Whether you are running a stroke support group, funding training, offering services to stroke survivors, or influencing policy as part of your SSO's activity, you will need to consider how to use the media to draw attention to your SSO and your activities.

In today's world, many of the media and promotion tools we use are digital, but there is also value in using more traditional media such as radio, newspapers and TV depending on your location. Below is an overview of platforms your SSO can explore:

- **Social Media** platforms like Instagram, Twitter and Facebook are a great place to start because they are free and impactful – according to research, a little over half of visits to fundraising pages come from social media.
- **Your Website** is your organisation's online persona and can go a long way to giving your work credibility. If you can't afford to hire a website developer, investigate options like Squarespace which allow you to create and manage a professional platform yourself. Alternatively, in place of a website, join the 93% of non-profits around the world that have a Facebook page.
- **Email marketing** is cheaper and less time consuming than other forms of marketing, and still impactful. To get a higher return on your efforts, ensure to personalize some of your emails to donors and supporters, so that they feel included in your SSO's activities.
- **Print Marketing** are great tools when you or your intended audience has limited access to, or engagement with, the internet. Although options like billboard advertising, and radio and TV can be expensive, if you target them correctly, they can reach large audiences. Alternatively, many people are engaged by well-designed, visually compelling flyers which you could distribute during events or via direct mail.
- **Press engagement** takes time to create good rapport with journalists and the press. Journalism is after all, a form of free advertising.

## CASE STUDY

# Media and Promotion: Association for Stroke and Aphasia Bulgaria



The Association for Stroke and Aphasia Bulgaria dedicated time to translating WSO's 2021 World Stroke Day posters, videos and Minutes Save Lives materials. The association's campaign received the support of Sofia Metropolitan and Municipality authorities. The Ministry of Health shared the campaign on its website, and across the capital Sofia, a city of 1.2 million people, the Minutes Save Lives video and posters were shown on the subway and bus stops.

The campaign reached across the 16 municipalities of Bulgaria with the campaign messages promoted on websites and in town centres. The association also managed to gain support from partners and supporters to cover the expenses of printing and sending the materials to the municipalities. The media coverage focused on stroke was unprecedented. Members of the Association for Stroke and Aphasia were interviewed on Code Health TV, Bulgaria on Air, Nova TV, and on Radio Varna. Print and online media coverage included the Bulgaria without smoke initiative, Confindustria Bulgaria, Bulgarian Telegraph Agency and Medinfo magazine.

On presenting a 2021 Best Campaign Award to the Association for Stroke and Aphasia, WSO's Campaign Committee highlighted the significant coverage generated in the national, local and specialist press, as well as on TV and radio. It was also noted that the engagement of the Ministry of Health will contribute to advancing quality stroke care in Bulgaria and improved outcomes for patients.



## Templates and resources

- [Here](#) is a helpful link to a social media guide.
- Here are two comprehensive guides to non-profit marketing and content plan development: [Donorbox](#) and [Grassroots Collective](#)



## Take away

**Your media and promotion activities should be shaped by your purpose, your beneficiaries and target audience, your priority activities and your budget. How you use the media will play a significant part in determining your SSO's influence and ultimately, how it advances its purpose.**

## 6.3 Alliances

We know from the SSO Global Mapping that many SSOs, including new and emerging SSOs, are operating beyond their own borders. Membership of other organizations and alliances with shared agendas is common at national, regional and international levels and collaboration is taking place along the entire stroke care pathway.

Just as you need a group of people to help your SSO establish and grow, so too can your SSO benefit by being connected to other organizations through membership or partnership.

An alliance is when two or more organizations come together to work towards a particular goal. This alliance may be a formal partnership, a coalition or a network. The key point is that your SSO can join with other organizations either formally or informally to help to achieve a shared mission.

Joining an alliance, partnership or network can help your SSO have greater impact because you can<sup>10</sup>:

- **Achieve increased reach** by mobilising more resources, namely people and funding.
- **Grow your visibility** with the public, policy makers and health professionals.
- **Make your message clearer** and more urgent for decision makers. One message from many organizations is more effective.
- **Improve your effectiveness** by providing opportunities to learn from each other.
- **Strengthen your negotiating power** with donors, governments and powerful stakeholders.
- **Enable greater participation** opportunities for people living with stroke.

**Connect to the SSO network!** WSO has a growing [network](#) of SSO members located in all regions of the world. These organizations range in size and focus but are all united in driving improved outcomes for stroke, whether through awareness of risk factors and signs of stroke, influencing policy, investing in research or providing life after stroke services. SSO network members have extensive experience and insights about involving people with lived experience, influencing policy makers and understanding the long-term needs of stroke survivors and carers.



10. Squire, C. (2012) Partnerships and Capacity Building, PLP.

## CASE STUDY

# Working in partnership: Stroke Association Support Network Ghana (SASNET-Ghana)



SASNET-Ghana works closely with the Ministry of Health, the NCD Control Programme of the Ghana Health Service and the World Heart Federation to reduce the burden of stroke and CVD, hypertension, obesity and diabetes in Ghana. SASNET-Ghana is a key collaborator in the CVD Score Card Project, an initiative of the World Heart Federation, which launched in Ghana in 2022.

Earlier this year, SASNET-Ghana co-organized a two-day CVD Score Card and Diabetes Roundtable which focused on barriers and solutions for primary and secondary prevention of CVD, diabetes and obesity, and to develop a national plan of action for implementation. By working in this partnership, SASNET-Ghana was not only able to increase its visibility with different stakeholders but also to increase the urgency for decision makers to take action.

In his keynote address at the Roundtable, Dr Hafez Adam Taher, Director of External Health Co-operation at the Ministry of Health, stressed that Ghana is at risk of losing a significant part of its workforce due to CVD, diabetes and obesity related issues. He also underlined the importance of collaborative working between the government and partner organizations.

The next steps include the development of an action plan with proposed solutions at patient and health system levels. The appropriate partner organizations will be identified to be part of the working groups to take forward implementation of the plan.



## Templates and resources

- [Boss on a Budget](#) video outlines “4 Steps to creating Non-profit Partnerships”.
- [Non-profit Finance Fund](#) has resources for Non-profit & Healthcare Partnerships.
- [FundsforNGOs](#) video focuses on how you can build an NGO Network.
- The Tropical Health and Education Trust sets out some valuable [partnership principles](#).



## Take away

*“The world doesn’t change one person at a time. It changes as networks of relationships form among people who discover they share a common cause and vision of what’s possible.” Margaret Wheatley*



# 7. Connections

Here are some links to connect your SSO to the global stroke community.

- World Stroke Organization: <https://www.world-stroke.org/>
- World Stroke Campaign: <https://www.world-stroke.org/world-stroke-day-campaign>
- Stroke Alliance For Europe: <https://www.safestroke.eu/>
- NCD Alliance: <https://ncdalliance.org/>
- [Stroke Connector](#) the online hub to connect SSOs and stroke advocates around the world and share advocacy and stroke support experience and best practice.
- [NCD Academy](#) NCD Academy equips frontline health workers with integrated, mobile-first education on NCD care. It provides courses on CVD and stroke prevention, cancer care and mental health.
- [WHO Knowledge Hub](#) A global information-sharing online platform to provide and exchange up-to-date evidence and comprehensive information.

Image: Singapore National Stroke Association





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