



**World Stroke
Organization**

ADVOCACY TOOLKIT

WORLD STROKE ORGANIZATION

one voice
One World Voice for Stroke

November 2016

CONTENTS

PREFACE	2
INTRODUCTION	
Global Stroke Advocacy	3
How to use this Toolkit	4
ADVOCATING TO ACHIEVE CHANGE	
What is advocacy?	5
Who is involved in advocacy	6
DEVELOPING YOUR ADVOCACY PLAN:	7
THE STEPS TO ACHIEVE CHANGE	
Step 1 – What do we want?	9
Step 2 – Who can give it to us?	11
Step 3 – What do they need to hear?	19
Step 4 – Who do they need to hear it from?	24
Step 5 – How do we get them to hear it?	35
Step 6 – What have we got?	46
Step 7 – What do we need to develop?	48
Step 8 – How do we begin?	51
Step 9 – How will we know it’s working, or not?	54
EXTENDED CASE STUDY	58
GLOSSARY	60
ABOUT WSP	61

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PREFACE

This toolkit is for individuals who seek to advance stroke policy, elevate the issue of stroke in his/her community and improve stroke outcomes by driving advocacy and change through governments and institutions.

There are many things that individuals can do to reduce their stroke risk and maximize their recovery from stroke. Public Awareness campaigns are important in helping people with this, as well as raising awareness about the impact of stroke and the importance of a good health care system for stroke.

Good government policy also plays an important role. Governments at a national, regional or city level make decisions about healthcare resources and regulations that can make a tremendous difference in stroke prevention, assessment treatment and rehabilitation.

The World Stroke Organization (WSO) with the support of several global stroke organizations developed this toolkit to help you and your institution increase community awareness about stroke and to advocate for better public policies and health systems to address stroke. This toolkit can be used to supplement some of your World Stroke Day Campaign efforts to advance the issue of stroke in your region.

Every local achievement helps with our global goals around stroke.

INTRODUCTION

Introducing the Advocacy Toolkit

This toolkit will help you advocate for improvements in the health system to address stroke (e.g. gain more funding for stroke units, improve the use of best practice guidelines, ensure better access to stroke treatments, rehabilitation services) in your region.

Your local advocacy can help create change across the country and even around the globe. Local can be within your own city, state, country, or region. The WSO has worked globally to improve action on stroke. But we also need local action. Every country makes its own decisions about health care, so your national and local advocacy will help turn global commitments into action that benefits your own community.

Stroke Advocacy at a Global Level

The WSO has a major focus on global policy, making sure that governments across the world take action on stroke. The WSO is the lead international body for stroke and has a relationship with the World Health Organization (WHO), working closely on key projects of interest, and being involved in WHO work on preventing non-communicable diseases (NCDs). The WSO also works with regional and national stroke organizations, as well as the Global [Non-communicable Diseases Alliance](#).

Key agreements include the [WHO Global Action Plan for the Prevention and Control of NCDs 2013-2020](#) and the United Nations [NCD Sustainable Development Goals](#).

You can use these global agreements and alliances to help achieve change at a local level.

HOW TO USE THIS TOOLKIT

This toolkit is a basic guide for advocating about stroke in your region. It outlines nine key steps for creating an advocacy plan, describes the most common tools and tactics in advocacy, and suggests how to use the tools well. It will help you develop a plan, build the right coalitions, and know who to target in your local advocacy.

The Toolkit is presented in nine sections, each outlining a step in the advocacy process. We encourage you to work through the nine steps using the template for an Advocacy Plan. Information about each step, along with tools and resources that will help you develop your thinking about what you need to do, is included in each section.

The development of your Advocacy plan will be an iterative process. You may need to go back to Step 1, your goal, as you work out who your key decision maker and target is, so you can make sure it will really resonate with him/her. You may need to move backwards and forwards through the plan, refining and improving each step until you get to the final product.

Using this toolkit, you will be able to plan your own advocacy, to suit your purpose, context, and needs.

ADVOCATING TO ACHIEVE CHANGE

What is advocacy?

The World Stroke Organization defines advocacy as activities that bring about change in policies, practices and attitudes of organizations and institutions about stroke.

Examples of advocacy around stroke include:

- advocating for a government strategy to address stroke in your country; or
- collecting and reporting on stroke data to show local health authorities that there is a need for new stroke services.

Advocacy is different to awareness raising, although you may need to raise awareness of a problem to strengthen your advocacy efforts

This toolkit focuses on advocacy because making a change in the system benefits everyone affected, and provides a longer-term solution. In other words, systems advocacy is about fixing things, for everyone, once and for all.

Advocacy is about more than just presenting facts and evidence to decision-makers. We need to understand why decision-makers may not want to make the changes we are asking for, and then work to persuade them.

The importance of local advocacy on stroke issues

Advocacy happens at different levels – national, regional, city, and international. The most successful advocacy joins up the different levels.

There has been important progress at the global level on stroke.

The WHO has established the [Global Action Plan](#) on non-communicable diseases, which includes addressing the global burden of stroke.

The WSO has developed:

- a) the [Global Stroke Bill of Rights](#), which identifies the aspects of care that are most important for all stroke survivors and caregivers from across the world.
- b) The [Roadmap for Quality Stroke Care](#) outlining the care that needs to be in place in different parts of the world.

These international documents identify the most important aspects of care that we can expect to see across the world as well as showing that there is global support and agreement on what needs to be in place for stroke. **Global developments need to be implemented at a local level to ensure that the best practice, evidence-based stroke services are provided.**

You can refer to international advocacy as part of your local efforts, as a way of showing your decision-maker that this local issue has important national and international consequences. The international documents can be very helpful in local advocacy, providing clear statements of what is needed to address stroke.

Advocacy at the country, region, or city level is required to ensure local authorities and nations implement the recommendations of the Global Action Plan on non-communicable diseases and the Global Stroke Bill of Rights.

Who is involved in advocacy?

Anyone can be! Most advocates are people who have experienced a problem first-hand and who are most determined to have the problem fixed.

As an individual clinician, survivor, caregiver¹ or as part of a Stroke Support Organization you have valuable experience and insight into what is needed in your community to make a difference in stroke. As an advocate, you can be a powerful voice for change.

As a citizen, you are able to take your experiences to elected officials. These officials are responsible for representing the people's view to Parliament and for helping make sure that the health system is effective.

¹In this context, "caregiver" refers to those people (generally spouses or family members) who take responsibility for the ongoing care of the person who has had a stroke

DEVELOPING YOUR ADVOCACY PLAN:

THE NINE STEPS TO ACHIEVE CHANGE

This section is a step-by-step guide to create an effective advocacy strategy. It takes you through nine key steps to develop an effective advocacy strategy²:

1. What do we want? (goals and objectives)
2. Who can give it to us? (key decision-makers)
3. What do they need to hear? (messages)
4. Who do they need to hear it from? (influencers, coalitions, alliances)
5. How do we get them to hear it? (delivery)
6. What have we got? (resources; strengths)
7. What do we need to develop? (challenges; gaps)
8. How do we begin? (first steps)
9. How will we know it's working, or not working? (evaluation)

As you work your way through each of the 9 steps, fill in the relevant section of the next page – The Advocacy Plan.

This will form your completed Advocacy Plan. It will be the document you use to communicate with others, to monitor your progress as you go, and to check if you are making the progress you planned. You will update it if and when your advocacy plans change.

Remember, you may need to move backwards and forwards through the nine steps as you develop your plan, improving and refining it as you go. It is not a linear process!

Each of the nine steps is presented with a set of worksheets, tools and templates you can use to help you develop and implement your Advocacy Plan.

My Advocacy Plan

1) What do we want? (goals and objectives)	
2) Who can give it to us? (key decision-makers)	
3) What do they need to hear? (messages)	
4) Who do they need to hear it from? (influences, coalitions, alliances)	
5) How do we get them to hear it? (delivery)	
6) What have we got? (resources; strengths)	
7) What do we need to develop? (challenges; gaps)	
8) How do we begin? (first steps)	
9) How will we know it's working, or not working? (evaluation)	

STEP 1: WHAT DO WE WANT?

Focus on a specific issue and change that you want

Your advocacy needs to be tightly focused on a specific issue to be the most effective.

One common error in advocacy is to focus on the problem or a very broad topic such as “improved health care for stroke patients”. The problem with this is that when you don’t request a specific change, it is easy for decision-makers to agree but not do anything about it.

Focus on a single goal. Trying to achieve many goals at once can also be difficult as it is hard to get a clear message.

Think about the specific problem you are trying to address, and the solution to the problem.

Look at local data to help you identify what need to change. This will help you advocate for a very specific change. For example, you might want to advocate for increased health care for people with stroke, but the specific change you need is for the government to fund two new stroke units in the next budget.

Your goal should be developed based on the gaps in your region but some examples of Advocacy Goals include

1. To obtain funding for a FAST campaign in my region/state/country
2. For government to develop a stroke strategy that will improve stroke services
3. To establish a stroke unit in my district
4. To expand my stroke unit to be a comprehensive stroke centre
5. To gain funding for a community based BP awareness campaign in my region
6. To seek a policy that will see stroke patients assessed for rehabilitation needs at multiple time points in their recovery
7. To seek government investment in a return to work program for young stroke survivors
8. To improve food labelling to support healthy choices

Your goal may be similar to these, or entirely different. It is important that you are able to demonstrate the need for the goal you seek in your area.

Focusing on a specific issue and using evidence



The Korean Stroke Society focused advocacy efforts on a specific issue: the necessity to widen new oral anticoagulant (NOAC) reimbursement coverage. **CASE STUDY**

They focused on two key imperatives:

- a) to generate evidence which showed clear medical unmet needs in Asian Atrial Fibrillation patients; and
- b) to bring important stakeholders, such as policy makers, media reporters and government officials, to the public discussion by unveiling evidence endorsing NOACs clinical value.

Clear goal for UK National Stroke Strategy



In the UK, in 2004, there was no national plan or strategy to improve stroke care. A National Stroke Strategy was required. The Stroke Association UK identified this as a goal and worked on a clear plan to advocate for this, targeting key decision makers in government. They released a Stroke Manifesto, and ran a Stroke is a Medical Emergency Campaign as well as promoting the outcomes of relevant research. A National Stroke Strategy was released by the UK government in 2007 transforming stroke services in the UK. **CASE STUDY**

7

Lobbying for better stroke care



Advocacy is at the heart of Stroke Action UK (SAUK) and this involves lobbying and influencing decision makers for better stroke care in partnership with stroke survivors and carers. Prior to the establishment of SAUK, there was no organised stroke care in the borough. SAUK continued to lobby local politicians, the local authority and health sector to invest in stroke services development. The impetus for change came when the 2010 Care Quality Commission (CQC) stroke report rated Enfield as one of the worst performing boroughs in the London region. This led to joint working with both the Enfield Council and the Enfield Primary Care Trust (PCT) at the time (now called Clinical Commissioning Group CCG) to carry out stakeholder consultations on how to develop the Enfield Stroke Pathway (ESP). **CASE STUDY**

The key steps for identifying your advocacy goal

Does a national stroke plan or NCD strategy exist in your country?

YES

Use the national stroke strategy, alongside national data measuring access to services/stroke care to find the biggest gap between the plan and what is actually provided to make your goal very specific.

NO

Can you advocate for the creation of a stroke strategy?

YES
Develop your
Advocacy
Plan!

Use existing World Stroke Organization materials (e.g. Road Map or Global Stroke Bill of Rights) or other global documents which set prevention targets (the [WHO NCD Global Action Plan](#) or the [WHO NCD Global Monitoring Framework](#)) as the starting point of your advocacy as the starting point of your advocacy.

NO

Look for any local data that describes stroke services in your area (e.g. Audits or registries). They can help you identify gaps against the services that are recommended in the WSO materials, or in your existing National Strategy.



See Worksheet 1.1 for Global Stroke Bill of Rights and Worksheet 1.2 Road Map.



If you do not have a stroke strategy and advocating for one is not the best way forward, the following checklists may help you determine what you need most in your region.

WORKSHEET 1.1 Global Stroke Bill of Rights Checklist

The Global Stroke Bill of Rights is an important priority for the World Stroke Organization. It provides a tool that can be used by individuals and organizations to communicate with stroke care providers and with governments and their agencies about what people affected by stroke think are the most important things in their recovery. Many aspects of care considered important by those affected by stroke, and included in this document, have been shown to reduce death and disability after stroke.

Use this checklist to note whether the rights that stroke survivors and their families see as critically important are available in your region. If not, you may choose one of these as your advocacy goal.

Any gaps you identify in this checklist may also allow you to use the Global Stroke Bill of Rights to strengthen another advocacy goal you may have chosen. For example, if you have chosen to advocate for more stroke units, you could use the Bill of Rights to talk about how important a specialized team and coordinated care is for survivors and their families, and how it has been identified as important by the WSO.

People with stroke in my area are able to	All the time	Sometimes	Rarely or never
Receive the best stroke care			
• Receive a rapid diagnosis			
• Receive treatment by a specialised team at all stages of recovery (in hospital and during rehabilitation).			
• Receive care that is well coordinated.			
• Access treatment regardless of financial situation, gender, culture or place of residence.			
• Receive treatment that is right for the individual considering age, gender, culture, goals and changing needs over time.			
Be informed and prepared			
• Be informed about the signs of stroke			
• Be fully informed, for as long as required, about what has happened and about living with stroke.			
Be supported in recovery			
• Be provided with hope for the best possible recovery			
• Receive psychological and emotional support in a form that best meets needs.			
• Be included in all aspects of society regardless of any disability			
• Receive support (financial or otherwise) to ensure care is provided longer term.			
• Be supported to return to work and/or to other activities chosen for participation after stroke.			
• Get access to formal and informal advocacy to assist with access to needed services			
• Be connected to other stroke survivors and caregivers so as to gain and provide support in recovery from stroke.			



WORKSHEET 1.2 The WSO Global Stroke Services Guideline and Action Plan: A Road Map for Quality Stroke Care

The WSO developed *The WSO Global Stroke Services Guideline and Action Plan: A Road Map for Quality Stroke Care (The Roadmap)* to provide a framework that could be used locally to implement, monitor and evaluate stroke services.

You can complete the checklists in the Roadmap to help you identify what aspects of stroke services you might choose for your advocacy goal.

The Roadmap outlines care and systems recommended in different settings, based on local health service capacity. It provides a step-by-step for users to:

- review their current stroke care delivery services,
- understand requirements for human resources and equipment,
- determine available systems and capacity for data collection, and
- develop an implementation plan to ensure core elements of stroke care are optimized.

The Roadmap helps you clearly identify elements of care that are not available or need improvement. It is therefore an important tool for your advocacy efforts. Local guidelines for stroke care, if they are available, can also be used.

How to use?

Users of this Roadmap should:

1. **Review** the sections relevant to their phase of stroke services;
2. **Complete an assessment** of current services and resources, current recommendations in place, and current data collection methods and access; then
3. **Develop an implementation plan** to ensure that these core elements are optimized and additional elements added to improve the stroke services they provide.

In each section of the stroke care continuum you will be prompted to review and assess local the structural elements and services available for stroke care. This will determine if they fall into the minimum, essential or advanced stroke services category

You can also look for any local data that describes stroke services in your area (e.g. audits or registries). They can help you identify gaps against the services that are recommended in the WSO materials, or in your existing National Strategy.



WORKSHEET 1.2 The WSO Global Stroke Services Guideline and Action Plan: A Road Map for Quality Stroke Care

In each section of the stroke care continuum you will be prompted to review and assess local the structural elements and services available for stroke care. This will determine if they fall into the minimum, essential or advanced stroke services category

A. Stroke Services and Resource Availability

Please review each of these lists and tick all services and resources that you currently have in place and available for providing stroke care. Once completed, review your responses to determine which category of stroke services you most closely fit into.

Minimum Healthcare Services	Essential Stroke Services (In addition to services listed under Minimal stroke services)	Advanced Stroke Services (In addition to services listed under Minimal and essential stroke services)
<ul style="list-style-type: none"> <input type="radio"/> Care provided in local communities without coordination across defined geographic regions <input type="radio"/> No access to diagnostic services or hospital care for hyperacute stroke treatment <input type="radio"/> Very limited access to physicians <ul style="list-style-type: none"> • Provide assessment skill development • Basic training in swallow screens and dysphagia management; and in temperature management <input type="radio"/> Variable access to healthcare workers (nurses or lay workers) <ul style="list-style-type: none"> • Basic training in swallow screens and dysphagia management; and in temperature management 	<ul style="list-style-type: none"> <input type="radio"/> Limited coordinated stroke care provided across geographically discrete regions <input type="radio"/> Stroke training programs for all levels of healthcare providers <input type="radio"/> Access to basic diagnostic services <input type="radio"/> Limited access to emergency medical services <input type="radio"/> Access to nurses and nursing assessment with stroke training <input type="radio"/> Access to physicians with stroke expertise (although may not be stroke specialists) <input type="radio"/> Access to acute thrombolysis with IV tPA <ul style="list-style-type: none"> • Intravenous tPA (Alteplase) 	<ul style="list-style-type: none"> <input type="radio"/> Fully coordinated stroke care provided across geographically discrete regions <ul style="list-style-type: none"> • Advanced stroke services rationalized to a smaller number of centres • Stroke pathways that define movement of stroke patients across region to higher and lower levels of services as required • Coordinated referral system • Provide telestroke consultations to smaller and more rural; centres • Ambulance bypass agreements in place • Repatriation agreements in place to transfer patients back to home communities • Printed stroke patient educational materials

B. Core Stroke Care Recommendations

For each best practice recommendation, indicate with a tick whether the described practice is in place as a routine part of care; in development for implementation; not implemented, meaning the service/resource may be available but it is not currently part of stroke care within your services; or, the service/resource/equipment is not available within your facilities, therefore not possible to implement.

Health System and Stroke Recognition Core Evidence-Based Recommendations	Applicable Level of Health Services Capacity for Stroke Care			Supporting Evidence	Self Assessment
	Minimum	Essential	Advanced		
A. Systems for Stroke Recognition and Response					
1. All members of the public should be able to recognize the signs and symptoms of stroke (e.g., FAST)	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	Evidence level: C	<input type="checkbox"/> In place <input type="checkbox"/> In development <input type="checkbox"/> Not implemented <input type="checkbox"/> Not available
2. All healthcare personnel should be trained to recognize the warning signs and symptoms of stroke	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	Evidence level: C	<input type="checkbox"/> In place <input type="checkbox"/> In development <input type="checkbox"/> Not implemented <input type="checkbox"/> Not available
3. All geographic regions should have a local emergency call number or system in place, such as 9-1-1		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	Evidence level: C	<input type="checkbox"/> In place <input type="checkbox"/> In development <input type="checkbox"/> Not implemented <input type="checkbox"/> Not available
4. Protocols should be in place in emergency call centres to mobilize EMS personnel to respond to a stroke call with high urgency		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	Evidence level: B	<input type="checkbox"/> In place <input type="checkbox"/> In development <input type="checkbox"/> Not implemented <input type="checkbox"/> Not available

Users will be provided with core evidence-based best practice recommendations related to processes of care that should be operational, based on level of services available; and, a list of key quality indicators to monitor levels of care provided and impact on patient and economic outcomes

To complete the checklists in the WSO Global Stroke Services Guideline and Action Plan: A Road Map for Quality Stroke Care go to: <http://www.world-stroke.org/education/roadmap-to-delivering-quality-stroke-care>

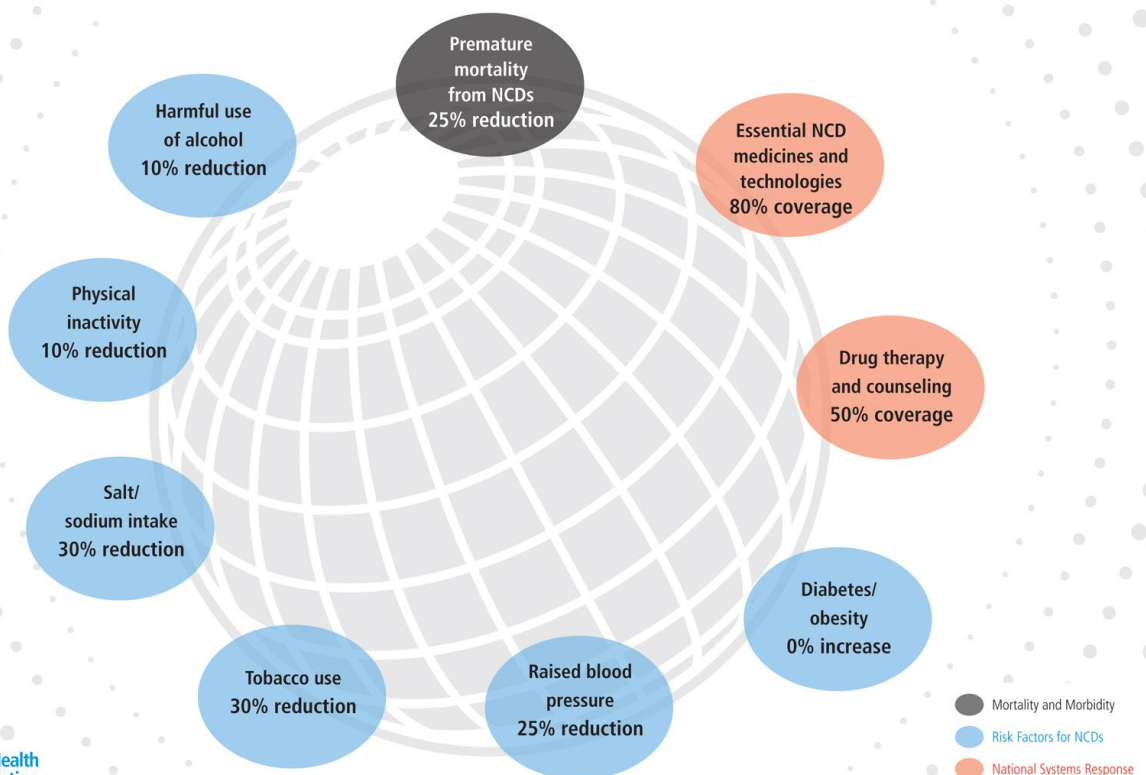
The World Health Organization Non-Communicable Disease Monitoring Framework

Following the Political Declaration on Noncommunicable Diseases (NCDs) adopted by the UN General Assembly in 2011, WHO developed a global monitoring framework to enable global tracking of progress in preventing and controlling major noncommunicable diseases - cardiovascular disease, cancer, chronic lung diseases and diabetes - and their key risk factors.

The framework comprises nine global targets and 25 indicators and will be up for adoption by Member States during the World Health Assembly in May 2013. Once adopted, Member States are encouraged to consider the development of national NCD targets and indicators building on the global framework.

The 9 voluntary global targets are aimed at combatting global mortality from the four main NCDs, accelerating action against the leading risk factors for NCDs and strengthening national health system responses. The mortality target - a 25% reduction in premature mortality from noncommunicable diseases by 2025 - has already been adopted by the World Health Assembly in May 2012.

Set of 9 voluntary global NCD targets for 2025



STEP 2: WHO CAN GIVE IT TO US?

When you are advocating for a specific change, you need identify the key decision-makers. **You need to know the people and institutions that you may need to convince, and work with, to make it happen.**

Your key target is the decision-maker(s) is the person with the formal authority to agree to the change that you want. For stroke, decision-makers might include Ministers in the Government, local health administrators, heads of organizations, or government departments.

Be specific about who the decision-maker is: not just “the Government” but a particular Minister who is in charge of the issue you want to change. If your decision-maker is within the health system, or even your local hospital, try to pinpoint the specific position(s) or person(s) who can make the decision you need.

You should be able to name your decision-maker. If you can only describe the target in general terms you will need to refine this step further. For example: if you want to advocate to the government, you may select the Minister for Health, the Secretary of the Department of Health and note the name of that person on your plan. You may have one or several targets.

You will also target people who may not be able to make the decision, but who can help you with your efforts. These people cannot make your goal happen, but they can influence the key decision-maker to approve it **(Worksheet 2.1)**.

We talk about these people (the influencers) in Step 4.



Once you have identified your target decision-maker(s), you need to **find out more about the person(s), so that you know how to best influence them.**

1. Why will he/she care about this goal – why will he/she want to make it happen (is it about prestige, saving money, better outcomes?). Different reasons will work for different people.
2. What will be the questions he/she will ask you about this goal and why it matters and is important.

Think carefully about the action you need them to take. Be as specific as possible and check that the action is within their power. Examples of actions you might need from a target decision maker include: introducing legislation, changing the rules around something, funding a new program, or increasing funding for an existing program



WORKSHEET 2.1 Understanding your target decision-maker

Consider the following questions to identify your key decision maker and to start to map out the best ways to influence them. If you have more than one key decision maker, complete a sheet for each one.

Question for analysis	Notes
Who is the key decision-maker who is the target of our advocacy?	
Why is this person the target of our advocacy? What decision can they make that addresses the problem?	
Why should they care about this issue?	
What is their position on your issue?	
How much do they know about this issue already?	
What would it take to persuade them to act?	
What are their passions and interests and how could that relate to your issue	
What have they said or done in the past that is relevant to your issue?	
Who do they listen to, and who influences their view?	
What does past experience suggest is persuasive for them? For example, are they most convinced by personal contact and stories, or by science and data?	
What action do you need them to take?	



WORKSHEET 2.2 Refining your key target

Write down the names of your possible key decision makers in the table below. Can he/she make the decision that will achieve your goal (approve funding/ agree to develop policy/establish the service)? If yes, then this person is the target of your advocacy. If not, then they may be a person who can help you reach your key decision maker.

Name	Able to make a decision that will achieve the goal (Y/N)	Why does the goal matter to them?	Key decision maker (target of advocacy) or influencer?

STEP 3: WHAT DO THEY NEED TO HEAR?

There are two parts to a good message:

- 1) why the advocacy goal is the right thing to do (the problem and solution)
- 2) why it is in the interests of the decision-maker to do it (the motivation)

When creating your messages, consider the following:

- **think about your target audience** – your message may vary depending on whether you're addressing the Minister, or a health administrator.
- **put yourself in the shoes of the decision-maker.** What does the decision-maker need? What is in it for them to provide what you are asking for? What do they need from you? Try to anticipate their concerns and provide data or arguments to address their concerns proactively. For example, if budgets are tight, a decision-maker might have concern about the increased funding you are requesting. Share how your proposal might save money in the long-term through reduced use of long term care services or increased productivity.
- **don't just focus on the problem.** You need to also talk about the solution and its benefits so that people understand what you are advocating for.
- **paint a picture for people.** Facts are important, but hearing about the human impact will create empathy and understanding. In the case of stroke, this could mean stories about patients being denied treatments that could make a difference.
- **talk about the relevant values** (eg fairness and equity), not the technical parts of the problem or the solution. For example, being able to show that there is unequal access to services, or that people in your area are worse off than people elsewhere.

To refine your key messages, write down the problem you are trying to solve, what the solution looks like and key messages to support your argument for change.

See Worksheet 3.1 (this also includes some examples)



EVIDENCE BASED ADVOCACY

An important part of advocacy is having clear information about the issue, and to be able to explain the problem and solution to people.

Use evidence to support your description of a problem, why the solution is the right one and impact the change will make. Make sure you have key information to support your argument.

This information can act as evidence to support your advocacy goal. You should also mention any relevant global agreements.

Your local health authority or Stroke Support organization or research body can be a good place to find facts and information.

Some useful sources of data, or policy documents to build your message include

1. The Global Stroke Bill of Rights Checklist
2. The WSO Roadmap
3. WHO NCD Global Action Plan
4. WHO NCD Global Monitoring Framework
5. Global Burden of Disease Study
<http://www.healthdata.org/gbd>
6. WHO Global Health Atlas
<http://apps.who.int/globalatlas/>

If your advocacy relates to an issue already covered by the Global Stroke Guidelines, the World Stroke Campaign, or one of the WHO or the Non-Communicable Diseases Alliance, use materials from these sources, to strengthen your arguments for change.

See
Worksheet 3.2



Stroke Monitoring at a National Level

The National Sentinel Stroke Audit (NSSA) monitored the rate of progress in stroke care and services in England, Wales and Northern Ireland on a two-year cycle from 1998 until 2010. It consisted of a clinical component which measured the quality of stroke care and an organizational component which measured the quality of stroke service organization.

This audit and follow-up audits demonstrated that audit helps improve the quality of care by involving trusts across the country in large-scale audit enabling them to compare their results to the national data.

For example, results from the initial audit showed that Wales was performing worse than elsewhere in the UK. This data was presented to the government as clear evidence that this trend was concerning and needed to be reversed and key recommendations to improve the situation were applied.

The process revealed that nationally conducted audit linked to a comprehensive dissemination programme was effective in stimulating improvements in the quality of care for patients with stroke. As a result, more patients were being managed on stroke units and multidisciplinary care became more widespread. It also identified areas where standard of care was still low, indicating which areas where skills and resources were still needed to achieve acceptable levels.



WORKSHEET 3.1 Developing key messages for your target decision maker(s)

The following sheet provides some key communication messages for various problems and solutions associated with stroke care. If your problem/solution is listed, select which messages will resonate with your target key decision maker. Add the ones you think will be powerful in your setting.

If you have multiple decision makers who need to hear different things, complete a worksheet for each one of them.

Look for local data (including data from high quality registers if available), or publications to strengthen your argument.

What is the problem?	What is the policy solution?	Key communication messages	My communication message (look for local data to strengthen your argument)
The general public do not know the warning signs of stroke.	Mass media campaign should promote the FAST message	<p>Time is brain. Early recognition makes a big difference.</p> <p>Knowing the signs of stroke and getting treatment quickly saves lives and improves recovery.</p> <p>Up to half of stroke cases could be treated with clot-busting treatments if they arrive within three hours of stroke onset to the hospital.</p> <p>Mass media campaigns have shown increased awareness of stroke symptoms and the importance of seeking emergency services immediately as a result of the FAST message.</p> <p>The FAST message should be communicated to the general public (e.g. through print, broadcast and online news, health columns, blogs features social media, community groups, community/ workplace newsletters.</p>	
People who have had a stroke are not being assessed quickly enough	Implement more stroke Units	<p>The characteristics of evidence-based Stroke Unit care are quite simple and should not be very difficult to implement in routine practice.</p> <p>The basic characteristics of Stroke Units are: dedicated units, specially trained staff, multidisciplinary team care, and procedures for diagnostic evaluation, acute monitoring, and acute treatment, early mobilization, and a very strong focus on rehabilitation.</p> <p>The combination of acute treatment and early rehabilitation seems to be one of the most important factors for effective SU care.</p> <p>International experience shows that it is possible to establish such Stroke Units both in large teaching hospitals as well as in smaller local hospitals, and with excellent clinical results.</p> <p>http://stroke.ahajournals.org/content/40/1/1.full#ref-1</p>	



cont...WORKSHEET 3.1 Developing key messages for your target decision maker(s)

What is the problem?	What is the policy solution?	Key communication messages	My communication message (look for local data to strengthen your argument)
Hospital stays following stroke are lengthy and high cost	Implement more stroke units	<p>Stroke Unit care is the most important treatment for stroke patients and the only treatment of acute stroke that has a major impact on the burden of stroke.</p> <p>The consequences of not implementing Stroke Units are that many stroke patients will die unnecessarily or will become dependent and require long-term institutional care. This will end up costing more in the long term.</p> <p>Stroke units are a cost effective approach. Establishing a Stroke Unit probably reduces the length of stay in hospital and the costs of stroke care compared to treatment in a general hospital.</p> <p>Specialized stroke unit care increases the chance of a good outcome by 14%. Stroke units will mean more people go home independent rather than be institutionalized with a severe disability, meaning they will require less help from government. They will often be able to return to work.</p> <p>Local and international guidelines recommend that all patients with stroke (ischaemic or haemorrhagic) should be admitted to a specialized stroke unit, which involves a designated ward with a specialized team.</p> <p>For every X people, Y will be home independent. We need them placed 1. in key, large hospitals, initially. 2. In our hospital, in ward X</p> <p>http://stroke.ahajournals.org/content/40/1/1.full#ref-1</p>	
Many people are left severely disabled following stroke and require government assistance	Implement more stroke units	See above	
Define your problem	Describe your solution		



WORKSHEET 3.2 Developing the evidence for your advocacy goal and messaging

Complete the following worksheet in relation to your advocacy goal. Use this information to help you refine and strengthen your advocacy message

	Key message/evidence
How many people are affected by the problem?	
What does the evidence, best practice guidelines, or policy suggest should happen?	
What happens to people at the moment?	
What does local data, including data from a high quality register if available, say about access to this treatment/care you are seeking to improve	
Why is access less than optimal - what is the cause of the problem?	
How many people would benefit from the problem being fixed?	
Has this issue been raised in the past? Have there been recommendations in the past about this issue?	
Is there any research that shows whether this problem will increase in the future, or have greater impact in the future?	
Are there any cost-effectiveness studies to show that solving the problem has an overall benefit to society?	
How do other countries deal with this problem? Providing your target decision-maker with examples from other places can help persuade them to act	
Does the issue reveal any inequalities in society, or make existing inequalities worse? For example, does the problem affect those who are poorer the worst?	

STEP 4: WHO DO THEY NEED TO HEAR IT FROM?

Many advocates think that they are the best people to deliver the message to target decision-makers, because they are working on the problem.

But even the best advocates will find it hard to create change alone.

The secret to successful advocacy is to gather key, critical voices to join yours in asking for change. To use your networks, and create new ones to achieve your goal.

A strong united voice: If you are an individual, your advocacy may be far more effective if you join forces with other individuals or organizations who care about the same issues. One of your key steps will be to determine whether you can make your message more powerful through partnership.

You may also feel that you cannot make the approach to your key decision maker. This is why alliances, and united approaches are so important. Others can make that approach with you, or help arrange meetings. Think carefully about who you will talk to to build a strong, united voice about the issue.

There are likely to be many groups and organizations that share your advocacy goals around stroke. These people and organizations are the influencers (ie those who influence decision makers) and include advisors, advisory bodies, civil society groups, individuals within a governing party, high profile individuals who are champions for your cause, scientific bodies.

Working together for a common cause can add great strength to your advocacy.

Working in partnership, to create a strong, united voice means that you create a united front on an issue, can share resources, and reach more people than any one organization or person could alone.

Decision makers are more likely to be influenced if they realize that there are a lot of people who care about an issue. Making partnerships is a key way to show how many people care.

Sometimes your key partners in advocacy will be people who can influence your key decision maker informally, talking about the importance of the issue in social situations. Consider who these people may be as you map out the individuals and organizations you want to approach to join you for a stroke, united voice.

You should find key people and organizations who have influence over the decision-maker. These individuals or organizations might become partners and help convince the decision-maker. In some cases, you need to first persuade them, in order for them to influence the main decision-maker.



See Worksheet 4.1.

The same message, from different mouths

Many players needed to be involved in advocating for the Ontario Stroke Strategy, only in different ways. It was a matter of telling the right stories in the right language to the right people. Many players were involved including hospitals, the health care system, health care providers, and stroke survivors and caregivers in order to convince government of the importance of investing in system changes for stroke care.



CASE STUDY

USING A COALITION OR FORMING AN ALLIANCE

You might work with others informally or more formally through a formal Coalition.

Coalitions often require a lot of work to keep everyone focused on the same advocacy goal.

In some areas, there may already be some alliances around stroke-related issues (e.g. prevention, improved disability support). If so, consider joining forces with them. The World Stroke Organization, your local SSO or stroke research body may know if any such alliances already exist.

It will also be important that you anticipate who your opposition, if any, will be. It can be helpful to reach out to those stakeholders/organizations proactively to understand their concerns in advance so you can address those concerns or attempt to neutralize their opposition messaging.



To learn more about Coalitions, see Worksheet 4.2.

Stroke Alliance for Europe

The Stroke Alliance for Europe (SAFE) is a coalition of Stroke Support Organizations (SSO's) each of which is based within a European country, and who come together for mutual support, campaigning, influencing and learning. Being part of an alliance enables new beginners and those only some way into the journey the opportunity to learn from others, and to get support.

One of SAFE's main objectives is to raise awareness and understanding of stroke and stroke prevention with policymakers at pan-European and national levels. SAFE is dedicated to muster the political will to help prevent stroke-related death and disability. SAFE recently coordinated a 250,000 euro research project on the burden of stroke in Europe, which will assist in enabling advocacy and awareness raising specific to each country based on both evidence and patient and family testimony.



CASE STUDY

WORKING WITH CONSUMERS

People affected by stroke, including stroke survivors and caregivers, can be powerful allies in advocacy efforts.

They are able to talk first hand of the impact of stroke, and to highlight the problems associated with poor care.

They can also reinforce the human element of the stroke burden.

Any people involved in advocacy plans will need to be supported and communication will need to be clear.

Use Worksheet 4.3

Stroke Action UK partners with stroke survivors and carers to lobby and influence decision makers for better stroke care through their Volunteer Stroke Ambassadors' development program.

Cross-NGO Alliance for better food labeling

The Australian Chronic Disease Alliance (ACDPA) was an alliance between the National Stroke Foundation, Cancer Council, Diabetes Australia, Kidney Health Australia and the Heart Foundation. They joined together to advocate for better food labelling in Australia to assist people to make healthy choices. By combining their voices, sharing their resources, and sending the same message multiple times to government, they, along with others, succeeded in having better food labelling introduced on all Australian processed foods.



CASE STUDY

Latin America Summit for Stroke

American Heart Association/American Stroke Association hosted the Latin American Summit, held on October 29-31 2015 in Santiago, Chile.

The Summit engaged key opinion leaders, health authorities, and other sectors, all of whom committed to develop a shared stroke agenda for one of the region's leading causes of death. The engagement of these diverse stakeholders provided the ingredients for a rich and productive discussion at the Summit that facilitated the exchange of best practices in stroke and actionable commitments to take forward to supporting this overall goal.

The Latin American Summit is a milestone in the AHA/ASA's international and stroke efforts to build a new constituency in region and explore how it's technical expertise can support the region's diverse interest and needs. The Summit resulted in launching a reputable stroke network across 10 countries and has the potential of extending its reach to others in the region of the Americas. Most promising, is the region's enthusiasm and commitment to the "La Carta de Santiago," a declaration and commitment to uptake of promising policy and systems changes necessary to impact stroke care and patient outcomes.

Over 22 organizations & 42 stroke leaders and ministry of health representatives attended from 10 countries attended the Latin American Summit.



CASE STUDY

Forming a Stroke Action Alliance in Nigeria

In 2013 Stroke Action Nigeria signed an important Memorandum of Understanding (MOU) with the Federal Ministry of Health to collaborate in mitigating stroke in Nigeria. It contained 6 key objectives: establish a reference group, stroke strategy, stroke register, national campaign, stroke education and stroke centre.

However, they faced challenges in implementing the MOU due to an unstable political climate, limited financial resources, and changes within the Federal Ministry of Health. To address this they formed the 'Stroke Action Alliance with Stroke Action UK and the Medical Association of Nigerians Across Great Britain, who signed up to help push the implementation of the MOU.

To help establish the first objective of establishing a Nigerian Stroke Reference Group, their partners assisted by holding fundraising activities during stroke month.

Their approach was strategic in terms of forming alliances with professional groups and the government. This enabled them to achieve excellent outcomes for progressive stroke services development. The NSRG was inaugurated on 16th September 2015.



CASE STUDY



WORKSHEET 4.1 Identifying your partners

Your key partners may be organizations with an interest in stroke, or individuals who may be able to influence your key decision maker (see Table 1). Use the worksheet to list out the organizations and/or individuals who may be willing to join your advocacy efforts. If you are unsure if they will join, list them and map out a plan for how you will explore this with them.

Remember: For any partnerships in advocacy, key factors for success include:

- Being clear about a shared goal for the partnership and the advocacy work
- Agreement about your messages and communication about your advocacy
- Having clear roles and responsibilities for everyone
- Understanding that different members of the partnership may bring different skills, viewpoints, and connections to the partnership, and valuing this diversity of contributions
- Regular communication to keep each other updated on progress and actions
- Agreed processes for working together – such as how important decisions will be made, how to make plans together, who will speak on behalf of the partnership
- Strong trusting relationships between advocates
- Accepting that while the major goal is shared, small details may differ between members, and that is fine as long as common ground is maintained

Table 1. Types of organizational partners you may work with

Type of group	Value in partnering	Considerations
Stroke specific organizations (SSOs)	<p>In many countries, there are national Stroke Support Organizations, NGOs working on the fight against stroke. These organizations offer information and advice to stroke patients. Some also provide other services or run awareness campaigns.</p> <p>There are also consumer and caregiver groups for those who are stroke-affected.</p> <p>Consumers and caregivers bring credibility of having experience with the issue and can share powerful stories.</p> <p>Consumer and caregiver groups have an understanding of the most common issues that affect their members, and can provide a strong collective voice.</p>	<p>Many Governments listen to SSOs because they are the voice of the people affected by stroke.</p> <p>Consumer and caregiver groups are often volunteer-run, with very little resources.</p> <p>Stroke groups are made up of stroke survivors, who may still experience effects from their stroke and face difficulties to being involved</p> <p>The caring responsibilities of caregivers means they often have little spare time</p>
Other non-communicable disease NGOs, consumer and caregiver groups, and general caregiver groups	<p>Many other health conditions may share common risk factors or challenges in accessing good-practice health care systems. Look for those involved in cancer, diabetes, heart disease or general health.</p>	<p>These groups may have their own goals for advocacy.</p> <p>Consumer and caregiver groups are often volunteer-run, with very few resources.</p>



Cont... Table 1. Types of organizational partners you may work with

Type of group	Value in partnering	Considerations
<p>Medical profession</p> <ul style="list-style-type: none"> – Clinical groups – Medical colleges – Medical association – Allied health groups – Individual experts and researches – Hospitals and universities 	<p>Medical professionals bring credibility of professional expertise.</p> <p>Medical professionals are particularly well-placed to speak with authority about issues relating to treatment and the health care system</p> <p>Medical professional associations tend to be very well-organized and already have strong relationships with decision-makers</p>	<p>Groups tend to organize at a country, region or city level, so find the one that is focused on the same level or in the same area as your target decision-maker</p>
<p>Community services</p> <ul style="list-style-type: none"> – Aged care and ageing – Disability – Rehabilitation – Home help 	<p>Community service organizations can provide a valuable perspective about the needs of stroke survivors and caregivers outside of the medical system. They are well-placed to speak about issues relating to long term care and recovery, and rehabilitation. They may also have common agendas, like a need for training on chronic diseases.</p>	<p>Try to find those that have a record in advocacy and who cover the same area as your target decision-maker and your issue</p>
<p>Other health care providers</p> <ul style="list-style-type: none"> – Hospitals – Emergency medical services 	<p>Unless these organizations are your target decision-maker, having them in your coalition can be very effective. Together you can demonstrate unity in support of your proposed policy solution and alleviate decision-maker concern about possible opposition from other constituencies.</p>	<p>Important to identify common goals and solutions and unify around those. You may not always agree on every issue but if you can demonstrate agreement on a specific proposal, it can be very influential with decision-makers.</p>
<p>Parliamentarians or Parliamentary groups</p>	<p>Some parliaments have interest groups, committees or caucuses for health issues or specific health conditions (including stroke or non-communicable diseases). These groups are made up of individual Parliamentarians with an interest in the issue and can act as champions within Parliament and respective political parties.</p>	<p>Politicians who represent an area that has a higher than average level of stroke, or who has a family connection to stroke, can also be a good champion for your cause.</p>
<p>Community, Faith Leaders</p>	<p>Community and faith leaders are often highly influential in the community and with other senior leaders, some of whom are likely to be a key decision maker. Getting them to agree that the issue is important, and that they want to help do something about it, can help with both formal and informal (social) approaches.</p>	
<p>Local authorities, government departments</p>	<p>It can be very useful to recruit support for your advocacy from government departments and authorities, other than your target decision-maker. Having different levels or players in government supporting your advocacy creates another path for persuading your target decision-maker</p>	



Table 2. Identifying Organizations which might be potential partners

List your potential Organizations:	Do they have a shared interest in my advocacy goal	Will they influence the decision maker	How will I approach them
Stroke Specific Groups			
Other non communicable disease groups and NGOs, caregiver groups			
Medical profession groups			
Community services			
Other health care providers			
Parliamentary groups			
Community / Faith Leaders			
Local authorities/government departments			
Other			



Table 2. Identifying Individuals who might be potential partners

List your potential Individuals:	Do they have a shared interest in my advocacy goal	Will they influence the decision maker	How will I approach them
Stroke survivors			
Carers			
Clinicians (medical, nursing, allied health)			
Researchers			
Celebrities			
Parliamentarians			



WORKSHEET 4.2 Setting up a coalition or alliance

Depending on your analysis about who the decision-maker needs to hear from, you may find it useful to form a coalition or alliance. Working in coalition can increase the reach and impact of other advocacy tools - you will have more groups asking people to sign petitions or to run events, often reaching different communities. Media is often very interested in coalitions or alliances because they provide a more diverse perspective, and sometimes unlikely allies can be a story in itself. Decision-makers find that dealing with coalitions on issues can simplify the process for them.

Looking at the organizations you identified in the worksheet above, now consider if it is worthwhile to approach them to set up a formal Coalition. Check to see if one might already exist before you do this.

Think about:

1. the purpose and reason for having a Coalition. Is it for a specific, short-term campaign (eg for funding of a specific stroke unit), or for longer-term purpose and reason for having a Coalition around the broad issue of stroke?
2. How you will **bring people together** to plan your joint approaches and discuss progress and goals. In some areas you may be able to do this face to face, but in other areas you may need teleconferencing, skype, etc.
3. the structure would be most effective for your purposes: Options include:
 - Many member organizations, with an agreement that 1-2 organizations act as the leaders, doing most of the work using their own existing resources, on behalf of the others
 - Many member organizations, with an organized structure of responsibility, decision making and resourcing
 - A smaller coalition where all decisions and work is shared using existing resources of the member organizations
 - A funded model where member organizations make a financial contribution to pay a staff member to implement the work of the coalition



Questions for consideration	Notes
<p>What is the purpose and reason for having a coalition?</p>	
<p>Which organizations share your interest in stroke, and your specific advocacy issue?</p>	
<p>What structure would be most useful for your purposes?</p>	
<p>How will you approach the senior people in each organization to find out if they would be open to working together?</p>	
<p>How will you bring together people from different organizations?</p>	
<p>How often would you meet as an alliance or coalition?</p>	
<p>What is important to you in terms of how the alliance or coalition will operate? What will be important to your potential collaborators?</p>	



WORKSHEET 4.3 Engaging consumers

There are many ways to involve consumers in your advocacy. This worksheet will help you consider some options that may be appropriate to your situation

Things to consider	Your notes
Which groups of consumers or grassroots supporters are most likely to influence your target decision-maker? Consider groups from the same area as your decision-maker, groups that are connected in some way to your decision-maker	
Does your issue lend itself to powerful personal stories from people affected by stroke?	
If you are planning to meet with decision-makers, would it be appropriate to include a consumer so that the decision-maker hears from consumers about the impact of the issue?	
If you are doing a petition or letter-writing campaign (See Step 5), consider how you will involve as many consumers and grassroots supporters as possible	
If you are hosting events (See Step 5), can you use these gatherings to engage consumers and grassroots supporters?	

Engaging consumers can be made even more effective when used with other tools in the following ways:

- involve consumers in meetings with decision-makers and influencers. If enough decision-makers hear from consumers about how the issue affects them, more of them will pay attention;
- consumers provide a ‘human interest’ story for media;
- encourage consumers to run their own events - they will have their own networks to invite, and may bring their own creativity to the events;
- consumers could take the lead in collecting signatures for petitions or letters, from amongst their own networks. They are able to tap into family, friends and work colleagues, all of whom may be much more likely to sign when asked by someone they know.

STEP 5: HOW DO WE GET THEM TO HEAR IT?

There are many ways that a target decision-maker could hear about your issue. These include:

- a) Communication channels (mass media, social media, etc)
- b) Opinion polls and surveys
- c) Meeting with decision-makers / lobbying
- d) Using Parliamentary and policy processes
- e) Petitions, letter, signature campaigns
- f) Events
- g) Running local activities in support of existing WSO campaigns.



See Step 5 Approaches for a more thorough outline of these various approaches.

Generally, the more channels you use, the better, but you do need to be careful not to overload your decision-maker.

Whilst generally the more often a target decision-maker reads or hears about an issue, the more likely it is that they will see it as something important, sometimes a step-by-step approach is better. In most cases, a mix of communication approaches is best, particularly a mix of medias (e.g. social media, mass media, earned and bought media) with personal contact.

Linking their message to personal stories

“I feel I've been left to fend for myself. As well as looking after my partner, I also have our 22 month old son to look after. I keep being told that I need to look after myself but I feel that there isn't the support to do it.”



CASE STUDY

The Stroke Association (England) used patient quotes from a survey they conducted in developing their message to petition the government for a new stroke strategy. Their message said that it is these stories, along with their survey which showed that 45% of all stroke survivors feel abandoned when they leave hospital, which highlighted that there are significant challenges with the delivery of stroke care and treatment which can only be solved through a new national strategy to drive improvements across England.

You may feel that you need to build your credibility with your decision maker. You can do this by building strong partnerships and a strong united voice (Step 4) and the WSO is also able to provide support for this.

You should decide on the best ways of communicating your messages to this particular decision-maker and for this particular issue. This will help make the best use of your time and energy.

Some questions to think about in deciding how to best get your decision-maker to hear your message:

- Where does the decision-maker get most of their information?
- Are there key people or groups they listen to?
- Are they most convinced by personal contact and stories, or by science and data?
- Are they more responsive to public information (eg through the media, or published reports) or to more personal contact and observations?

Positioning request as a “win” rather than an “ask”



CASE STUDY

Given the Heart and Stroke Foundation of Canada did not have strong working relationship with Government at the time of wanting to implement the Ontario Stroke Strategy. The government had many other health care priorities; so an important tactic was to position stroke care as a “win for government” rather than an “ask”.



See Worksheet 5.1 to map out the best way to get your message across

Involving decision makers in strategic working groups

In advocating for the Ontario stroke strategy, the Heart and Stroke Foundation met with government officials, including the Minister of Health, and Foundation volunteers (many of whom were stroke survivors) met with their local members of parliament (again including the Minister of Health). Key bureaucrats were involved in all working groups and panels and became important champions. They provided advice on how to fit a stroke strategy within the Ministry’s policies and priorities and how to speak its language. They became strong advocates and helped build commitment and ownership within the government. Two well-known and high profile stroke survivors (a former high ranking politician and a well-known business man) spoke at a key event attended by important government officials.



CASE STUDY



WORKSHEET 5.1 Selecting the right approach for your situation

As noted in Part 1, there are various tools to help get your message to your target decision-maker including:

- a) Communication channels
- b) Opinion polls and surveys
- c) Meeting with decision makers / lobbying
- d) Using Parliamentary and policy processes
- e) Grassroots campaigning: Petitions, letters, signature campaigns
- f) Events
- g) Running local activities in support of existing WSO campaigns

Because there are so many possible approaches to use, you will need to carefully select the best approach to influence your key decision maker. Doing everything is not necessarily the best approach. Complete the following table to identify the best approach for your situation. A more detailed description of each approach is given below the Worksheet

Your situation	Which approach help	My best approach
You need to educate decision makers about stroke issues and make them aware of what they can do to address the problem	<ul style="list-style-type: none"> ● Meeting with decision makers / lobbying ● Grassroots campaigning ● Using Parliamentary and policy processes ● Communication Channels 	
You need to show that there is broad agreement in the stroke community about the change that is needed.	<ul style="list-style-type: none"> ● Coalitions and alliances ● Meeting with decision makers / lobbying 	
You want to make visible the amount of community support and interest in addressing stroke	<ul style="list-style-type: none"> ● Communication channels ● Events ● Grassroots campaigning ● Engaging consumers ● Meeting with decision makers ● Opinion polls and surveys 	
You need to build a relationship with decision maker	<ul style="list-style-type: none"> ● Meeting with decision makers / lobbying ● Using Parliamentary and policy processes 	
You want to influence other professionals to bring them on board	<ul style="list-style-type: none"> ● Alliances and coalitions ● Communication channels 	

A description of each approach is provided on the following pages.



Communication channels

There are many different channels for communicating with target audiences (whether the decision-maker, influencers or the community). This table identifies the most common channels for communicating in health, and the benefits, reach, and considerations of each. Please refer to this as you consider your options for how to best get your message to the decision maker.

If you decide that you need to raise awareness of the issue within your community using an awareness campaign and tools like social media, you will need to select your target audiences and channels of communication carefully. The WSO has developed a Campaign toolkit as part of the World Stroke Campaign. You can find more about this here

http://www.worldstrokecampaign.org/images/wsd-2016/wsd-2016-toolkit/Campaign_Toolkit_Overview_v3.pdf

Table 1. Choosing the most appropriate communication channels

Channel	Benefits and reach	Considerations
Presentation at conferences	<ul style="list-style-type: none"> • Good if you are trying to reach a professional audience and those already interested in the issue of stroke • You have control over the content and message • you may be able to link the presentation to some media coverage 	<p>Can be a long lead time Not accessible to anyone not attending the conference</p>
Papers in professional journals and newsletters	<ul style="list-style-type: none"> • Highly targeted - good if you are trying to reach a professional audience and those already interested in the issue of stroke • Low cost • Control over content and message • You may be able to get media interest in a published article 	<p>Can be a very long lead time Relatively small audience reach Only reaches those who are well-educated and relatively privileged</p>
Social media	<ul style="list-style-type: none"> • You have control over the content and message and timing • Can spread rapidly • Reaches people who may not already be familiar with the issue, and generate interaction on line • Can be no or low cost, likely to be worthwhile to pay for promoted posts 	<p>If your issue is polarising, social media activity can provide an opening for opposing arguments, and you cannot control the resulting conversation. Although online, your story and message may not spread very far. Social channels rely on good digital content, and well-established networks and champions to be effective communication tools</p>
Other media (eg radio, television, newspapers)	<ul style="list-style-type: none"> • Reaches people who may not already be familiar with the issue 	<ul style="list-style-type: none"> • Someone else decides if your content is used, and the angle of the story, and can include other material and viewpoints • Timing, placement, and depth of coverage is in the hands of the media outlet
Face-to-face meetings with decision-maker	<ul style="list-style-type: none"> • Direct access to the person who can make the decision you need • Opportunity for them to engage more deeply with the issue, and to understand the impact of the problem 	<p>Can be hard to get appointments with target decision-makers, as they tend to be very busy. It is even harder if you don't already have a relationship with them or they don't want to hear what you have to say</p>
Bought ad space in print, broadcast or online	<ul style="list-style-type: none"> • You have control over the content, look and message 	<p>Can be expensive, although online will generally be much cheaper than print.</p>



The following tables are examples from Stroke UK of how to identify and segment audiences in order to identify their channels of communication.

Table 2. Segmenting your target audience

Media	Target audience
National print, broadcast and online news, health columnists, blogs and features	TIA survivors, stroke survivors, those at risk and their families and carers, Stroke Association supporters, health professionals
Regional print, broadcast and online news and features	TIA survivors, those at risk and their families and carers, Stroke Association supporters, health and social care professionals
Woman's (monthlies and weeklies) and grey press	TIA survivors, those at risk and their families
Health and social care trade	Stroke, medical and health and social care professionals
BME media	BME communities (Black, South Asian)
Internal communications	Staff and volunteers

Table 3. Segmenting your target audience for social media

Channel	Audience	Reasoning
Facebook	Stroke-affected and supporters	With 43% of the UK population having a Facebook account this platform is the place to engage with our broadest of key audiences ^[1] . Targeting could allow us to reach professional and political audiences, however other networks offer a better route to these audiences.
Twitter	Supporters and professional	With only 19% of the UK population on Twitter and with the majority of tweets coming from a small sub set of this group it would be hard to reach many stroke-affected groups via this channel ^[2] . However with the number of professionals and politicians on this channel, and how other campaigns are using this network it makes sense for us to focus our efforts to reach these groups on Twitter ^[3] .
LinkedIn	Professional	As this network is the market leader for professional social networking then this will be our chosen route to reach this key audience. The network also has a number of groups which can be used to reach our target audiences ^[4] .
Instagram	Supporters and stroke-affected	Younger and working age supporters (78% of users are between 18-49) prolific on this platform, especially in sharing images related to fundraising events. Also in engaging with emotive images.
Blog	Various	The blog will be a platform to inform and create conversation in the longer form. It will be a place to drive traffic from our social channels in the first instance, and content will be generated by different teams across the charity.

Key Audience	Segment
Stroke-Affected	Older (65+) survivors
	Working age survivors
	Carers/family members
Supporters	Corporate supporters, major donors and celebrities, volunteers
	Stroke-connected, empty nesters (55-74)
	Stroke-aware, mid-life, pressured (35-54)
	Stroke-cause followers, youthful idealists (18-34)
Professional	Health care professionals
	Research organisations
	Voluntary sector
	Social care
	Parliamentary and political

^[1] <http://socialmedialondon.co.uk/digital-social-mobile-statistics-2015/>

^[2] <http://socialmedialondon.co.uk/digital-social-mobile-statistics-2015/>

^[3] <http://socialmedialondon.co.uk/digital-social-mobile-statistics-2015/> &

<http://www.theguardian.com/housing-network/2016/jan/11/social-housing-tenants-policy-activism-twitter> &

<http://www.paulsimpsonconsulting.co.uk/do-facebook-likes-and-hashtags-exert-influence-over-serious-minded-politicians>

^[4] https://www.linkedin.com/vsearch/g?orig=T&RNV&rsid=34459681453026153301&keywords=cardiovascular&trk=vsrp_groups_sel&trkInfo=VSRPsearchId%3A34459681453026153301%2CVSRPcmpt%3Atrans_nav



Using World Stroke Day to leverage off the Global Stroke Discussion

What is World Stroke Day?

The premier event of the World Stroke Campaign is World Stroke Day. It was established by the World Stroke Organization in 2006 and takes place globally every year on the **29th October**. So that is this Saturday.

It aims to raise awareness about the disease and unite people all over the world in the fight against stroke and advocacy efforts.

Together we
can conquer
stroke

A key objective of World Stroke Day is to get as many people as possible from around the world talking about stroke on **29 October**.

Why is World Stroke Day so important?

Stroke is the leading cause of disability and the second leading cause of death globally, and it can happen to anyone at any age.

World Stroke Day is an important opportunity to drive awareness of stroke among the public, governments and media outlets globally.

It is a great opportunity to leverage off the global stroke discussion to achieve the awareness and advocacy objectives of your own organizations. In past years World Stroke Day was a trending topic on twitter; and there were 12.9 billion opportunities to read online articles about World Stroke; so that is a huge conversation to be taking advantage of.

Social media

Join the year-round global conversation on Facebook and Twitter.

Download the World Stroke Campaign Toolkit

In 2016, thanks to the help of global volunteers the Toolkit was available in 20+ languages. It includes brochures, posters, infographics, videos, press releases, ready-made key message tweets, and more.



Follow
[@WStrokeCampaign](https://twitter.com/WStrokeCampaign)

[facebook.com/
worldstrokecampaign](https://facebook.com/worldstrokecampaign)

facebook



Opinion polls and surveys

Sometimes you need to show how much public support there is for your issue as part of persuading the decision-maker to follow your recommendation.

One way to do this is to run an opinion poll or a survey. **Opinion polls or community surveys can be very useful if:**

- You have strong opponents and you need to show that you are speaking on behalf of many people in the community;
- The decision-maker is likely to act if they believe that most of the community wants them to;
- The decision-maker thinks that the community doesn't care about the issue;
- You want to create a media story about your issue and need some data for the story.

There are three main options for opinion polls and surveys:

1. **Buy one or two questions in an existing “omnibus” survey that is run by a commercial market research company.**

This option is less expensive than running an entire survey and the results are available fairly quickly. This option is best when you want an opinion poll of the general community;

2. **Partner with a research group or large civil society organization to run a survey about your issue.**

This can take a long time, but allows you to ask more questions;

1. **Run a simple survey of your members or supporters.**

This can be very useful if you want a survey of a particular group of people (eg stroke patients in your own city or state) or where you cannot afford one of the other options above. There are many websites for creating surveys² that can then be shared by email, or you could use a paper survey at events or in locations where your supporters gather.

When you have finished your survey, the main purpose is to use it to persuade your target decision-maker to take action. It can also be useful to raise awareness.

Some ways to use your information:

- Write to your decision-maker to tell them you have some new data about the issue and request a meeting to tell them about it;
- A media story about the results of the survey or opinion poll. In this you can again ask the decision-maker to act, and raise awareness about your issue;
- Sharing it with your advocacy partners so that they can also use it.

²Try Survey Monkey, typeform, or Survey Gizmo



Meeting with decision makers / lobbying

Why meet with decision-makers?

One of the most effective ways to present your case to decision-makers is to do it face-to-face, where you can gauge their reaction, answer their questions, and make a specific request for them to act. Decision-makers receive a lot of letters and petitions, and hear about a lot of issues. We know that if people make the effort to meet with them personally, it tells them that this is an issue that people care about deeply.

When is it most useful?

You should always offer to meet with the decision-maker. When you first start your campaign, you should write to the decision-maker about the issue, your proposed solution and what you want them to do about it. In this first letter, you should offer to meet with decision-maker. This gives them the first chance to fix the problem, and for you to find out where they stand on the issue.

How to combine with other tools to increase impact.

If you have been collecting signatures on a petition or letter, you could meet with the decision-maker to present the petition and ask for their response. If you have involved consumers in your advocacy, include a consumer in the meeting so they can share their story with the decision-maker. If you have formed an alliance with other organizations, take at least one person from one of your alliance partners, as it will help the decision-maker see the wide support for the campaign.

Top tips for meeting with decision-makers

1. Do some research on the decision-maker so you understand their background and interests and can tailor your briefing to their background and interests (See Worksheet 2.1 for reminder)
2. Decide beforehand what you want to achieve from your meeting, and practice what you will say (why should they care, why they should do something about the problem, and what action can they take)
3. Think about what questions they may ask or problems they may raise. Common questions are about the size of the problem, and the cost of the solution.
4. Have a clear request of the decision-maker. Be clear with them about what you want them to do as a result of your meeting
5. Agree on roles for the 2-3 people attending the meeting. Who will lead the meeting? who will take notes? what will each of you say?
6. Leave a short briefing paper (1-2 pages) summarizing the issue and what you want them to do about it. Some examples, or ones you may use can be found here <<insert link>>
7. After the meeting, send a thank you note or email, confirming the key topics of the discussion, any information discussed in the meeting, and any promise made by the decision-maker

Most common mistakes when meeting with decision-makers

1. Not being able to clearly and briefly explain the problem, evidence for the problem, or the solution
2. Not keeping to time. Decision-makers, particularly politicians, are very busy. Show that you respect their time by arriving early, and being prepared to complete your meeting 5 minutes before the scheduled end time
3. Spending too much time talking about your organization or the problem, and not enough time talking about the solution and what the decision-maker can do about it
4. Talking 'at' the decision-maker, rather than asking them questions that help you understand their perspective
5. Treating the meeting as if it is about educating the decision-maker, rather than it being about persuading them to act, and not having a clear request for action from them
6. When people in the group are not coordinated in their messages



Using Parliamentary, and policy processes

There are many policy and Parliamentary processes that you can use. These differ from country to country, however in most places, you should consider if any of the following would be useful for your advocacy:

- **Elections** – before elections, political parties and candidates will be more open than usual to meeting with community and expert groups and listening to recommendations that they might act on. You can use this time to promote your advocacy goal
- **Budget cycles** – each year, government departments will be preparing a budget for the year ahead. Consider contacting your local health department or Minister to ask how to make sure that the government includes funding for your issue in the next budget
- **Public Inquiries** – in many areas, governments can run investigations or studies into particular issues. These usually include involving the public, and so you might be able to write a submission or present to the Inquiry.
- **Parliamentary supporters or Friends groups** – finding supporters in Parliament can be very helpful. They can give advice on how to speak with other Parliamentarians, publicly support your issue, or ask questions of your target decision-maker in Parliament. To find supporters for your cause, do some research to see if any Parliamentarians have had experience of stroke (personally, as a carer, or in their previous career). Some Parliaments are able to create special interest groups or “Friends” groups, made up of Parliamentarians from all parties who have a personal interest in particular issues. Find out if your Parliament has one for stroke. If not, consider finding an individual Parliamentarian supporter who can help set up a group in Parliament.



Grassroots campaigning, petitions, letters, signature campaigns

If you think the decision maker will be persuaded by seeing how many people care about the issue AND you know that lots of people care and would sign a petition or letter, then this is an appropriate tool.

There are a range of options for this collecting signatures for a petition or letter. Many online petition websites now exist where anyone can start a petition (e.g. [Change.org](https://www.change.org/)). The keys to a good petition are: an interesting story; an explanation of how signing the petition will help the campaign; a clear request of the target; and a way to make sure the petition reaches as many people as possible.

If an online petition, then your email list and social media accounts will be key.

If you are collecting signatures by hard copy, then you need to have a lot of ways of getting in front of people to ask them to sign. This might mean attending fundraising events, support groups, rehabilitation centres, waiting rooms of specialists, etc.

Using it with other tools for increased impact - holding community events is a good opportunity to get people to sign things. If you have a strong petition, you can also get media coverage about the positive response to the petition. If you plan to present the petition in person to the decision-maker, this is another good opportunity for media.

Events

Why hold events?

Public events are a great way to help spread the word about your campaign, and to make your issue well known. You can also design an event that highlights the problem you are trying to solve, that recruits new supporters, or that educates the decision-maker about the issue.

How to hold an effective advocacy event:

Think about your main purpose in holding the event, then design it to match. For example, if the main purpose is to draw public attention to your campaign, then it needs to be attention grabbing and in a public space. If the main purpose is to educate the decision-maker, then you should choose a time and location that suits the decision-maker.

You can increase the impact of your event by combining it with some other tools. An event can be designed to attract media coverage or to attract new supporters. An event held with coalition partners is a powerful way for organizations to work together and to show a unified support for the campaign.

The table on the following page provides examples of types of event.



Table 2. Example of each event by purpose

Purpose	Examples of events
Educate decision-maker	<ul style="list-style-type: none"> • small event where decision-maker can meet with people directly affected and can hear their stories eg afternoon or morning tea • event on site where stroke patients and survivors spend time (eg a rehabilitation unit)
Show public support for an issue	<ul style="list-style-type: none"> • rally or forum • many small community events held during a specific week • virtual event via social media.
Recruit supporters	<ul style="list-style-type: none"> • having a stall at a market, festival or community event where people can learn about your campaign and sign-up • run a seminar, forum or movie screening, where people can learn more about the issue then sign-up to support the campaign
Draw public attention to your campaign or the issue	<ul style="list-style-type: none"> • public stunt, e.g. a Guinness World Record; Chef Jamie Oliver filling a school bus With 57 tons of "Sugar" to show how much sugar is contained in flavored milk.

Run local activities in support of existing campaigns

Why use existing campaigns?

Global campaigns run by WSO provide a great base for running a local campaign. By using the materials and messages of global campaigns, changed for the local context, you can run great advocacy campaigns even with very limited resources. Using existing campaigns can also save you the time and effort of creating a campaign from scratch.

And you could look beyond WSO campaigns as well. Are any organizations in your part of the world already advocating on stroke issues? Could you join forces, or could you run a local campaign in your area that builds on their campaign?

How to support existing campaigns

The WSO has a three year plan for the World Stroke Campaign and WSD, with a different theme each year. The themes could be used for your local advocacy, particularly for media stories or a reason to approach decision-makers for action.

Materials from all the World Stroke Campaign work can be found on the website www.worldstrokecampaign.org. You will also find case studies and examples of how people in other parts of the world have done it.

STEP 6: WHAT HAVE WE GOT?

In order to create a realistic plan for your advocacy campaign, you need to think about how much you can do and consider how you / your organization can work effectively.

Some things to consider:

1. What are the resources that you can bring to your advocacy?

These might be financial (committing funding to meetings, travel, development of materials, etc), professional (your experience as a clinician or a survivor), connections (to organizations or people who can add their voice to you) or knowledge (what you know about the problem and about the solution, your evidence for change)

2. What is the source of your credibility to speak on this issue?

Advocates will bring their own expertise to any conversation, whether that experience and expertise relates to your role as a clinician, a stroke survivor or family member, or a member of a stroke related non government organization or stroke support organization.

You can also build your credibility by:

- Building strong alliances with well respected organizations and individuals who call for action around your goal
- Talking to the WSO about support and credentialing
- Participating in advocacy training
- Supporting all your arguments with evidence, data and policy documents that support the need for action
- Developing position statements or other documents that you can use with others to justify your position

3. How can you make the most of your resources and credibility?

4. What groups are you already connected with that might support you in your advocacy.

Think about the people who are most likely to be influenced by what you know, your experience and expertise. Start to build your strong, united voice with those who you can influence most and get them to help you build it further. Start small, and grow.

5. What relationships do you already have with decision makers or influencers?



WORKSHEET 6.1 Mapping out your assets and resources

<p>What are the resources (financial, professional, connections, people, knowledge) that you can bring to your advocacy?</p>	<p>Financial</p> <p>Professional</p> <p>Connections</p> <p>People</p> <p>Knowledge</p>
<p>What is the source of your credibility to speak on this issue?</p>	
<p>How can you make the most of your resources and credibility?</p>	
<p>What groups are you already connected with that might support you in your advocacy</p>	
<p>What relationships do you already have with decision makers or influencers?</p>	
<p>How can you make the most of your resources and credibility?</p>	

STEP 7: WHAT DO WE NEED TO DEVELOP?

Once you have identified what resources you have, you will also be aware of any resources you are missing.

The most important gaps in advocacy are usually around knowledge, specific skills (eg online campaigning), or connections (relationship and credibility with the target decision-maker).

The most effective way to address any gaps in your resources is to partner with organizations that have skills, knowledge, experience, or connections that you do not. If you do this, it's important to think as a group how to best work together, and how to mitigate any risks that might arise from working together.

Examples of working together

- Research bodies have access to lots of information and data, and experience in working with the media and expert spokespeople, but no community connections or experience in reaching out to communities online. A partnership between a research body, a consumer group, and engaging the support of an online campaigning platform, would provide a very effective alliance.
- A community service organization sees first hand the problems faced by stroke survivors who are unable to access rehabilitation services, and has many consumers and caregivers who can share their stories. By partnering with a medical association or clinical groups, the advocacy initiative can provide both perspectives on the issue, and draw on any evidence and data held by clinicians.

If there are no other groups to partner with to help with your advocacy, consider contacting the WSO for ideas, or to connect with other stroke organizations in your region. It can often be very useful to just connect with others to discuss your ideas.



WORKSHEET 7.1 Identifying how to fill the gaps

Use Worksheet 7.1 to work out what you need to develop, or create, to make a start on your advocacy. What you need to develop will depend on the resources you have, and you will need to prioritize them. Examples of what you may need to develop are relationships with key influencers (so setting up meetings with them); a business case/project proposal for funding, a budget for the advocacy work, or for the ask that you are making of government; the things you might want to develop

	What do I have?	What do I need to develop?
What are the resources (financial, professional, connections, people, knowledge) that you can bring to your advocacy?	Financial Professional Connections People Knowledge	
What is the source of your credibility to speak on this issue?		
How can you make the most of your resources and credibility?		
What groups are you already connected with that might support you in your advocacy		
What relationships do you already have with decision makers or influencers?		
How can you make the most of your resources and credibility?		



TEMPLATE 7.1 Project proposal template

If you are seeking funding for stroke services or a Campaign, you may need to develop a project proposal.

This should include the goal of the work, a strong, evidence based rationale for why it is needed and why your proposal will help solve the problem, what the work will look like, a budget and the way in which you will measure its success. The proposals do not need to be long but can be left behind after meetings, or sent to the key decision makers as part of your advocacy efforts. An outline of a project proposal may include the following:

1. Goals and objectives
2. Rationale
3. Description of work to be undertaken
4. Roles and responsibilities
5. Key milestones
6. Budget
7. Monitoring and evaluation

Some examples of project proposals for work done by others are on the WSO website.

STEP 8 HOW DO WE BEGIN?

The earlier steps in creating your advocacy strategy focused on how to plan and set up your advocacy campaign.

Once that is complete, it is time to move to action.

This means breaking down your ideas for your strategy into specific actions and timeframes, and assigning responsibility to people. This is particularly important if you are working with a team of people or organizations.

During this process, you need to consider questions such as:

- Are there short-term goals that lead towards the change that we are advocating for?
- What information or evidence are we missing? What are the next steps in getting that information or evidence?
- How should I first make contact with the target decision-maker?
- What are my key milestones and when will I aim to deliver them?



You will need to develop a plan for your advocacy efforts, that maps out what you want to achieve and when. You may also need to consider who will be responsible for each step of your plan.

A table like this can be developed using Excel or Word and regularly updated as you monitor progress (we talk about this in Step 9)

FIGURE 8.1 Example of a Timeline Table

ITEM	Nov 16	Dec 16	Jan 17	Feb 17	Mar 17	Apr 17	May 17	Jun 17	Jul 17	Aug 17	Who is responsible?
Advocacy issue identified											
Clear advocacy goal & objectives developed											
Target audience identified											
Partnerships and supportive coalitions developed											
Key messages developed											
Key communication channels identified											
Meetings with key decision makers											
Fundraising											
Implementation of advocacy goal Eg grassroots campaign Running petition											



Use country / region specific evidence to build your case.

You can find some stroke stats specific to your country in a range of places including the World Health Organizations Atlas of Global Heart Disease and Stroke; and within the Global Burden of Disease study.

You may also be able to access local data that describes stroke services in your areas such as audits or registries; or data may already be collated in your country's national stroke strategy (if it has one).

Your local Stroke Support Organizations may also have a repository of local states which have been collected via surveys.

WORKSHEET 8.1 Building the Evidence Case

Global Stroke Stats	Fill in the stats for your country
Globally 17 million people suffer a stroke each year. (1)	
Each year 6.5 million people die from stroke worldwide. (2)	
At any one time there are 26 million stroke survivors around the world. (2)	
Stroke is responsible for more deaths annually than those attributed to AIDS, tuberculosis and malaria combined. (3)	
Two out of every 3 people who suffer from a stroke live in low-and middle-income countries. (4)	
From 2000 to 2008, the overall stroke incidence rates in low- to middle-income countries exceeded rates of high-income countries by 20%. (4)	
The global burden of stroke is projected to rise around 38 million DALYs (years of healthy life lost) in 1990 to 61 million DALYs in 2020. (5)	
Stroke is one of the leading causes of long-term disability worldwide. (6)	
Specialized stroke unit care increases the chance of a good outcome by 14%. (7)	
Clot-busting drugs (tPA or thrombolysis) increase the chance of a good outcome by 14%. (8)	
Clot retrieval treatment increases the chance of a good outcome by more than 50%. (9)	

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STEP 9: HOW WILL WE KNOW IF IT'S WORKING, OR NOT?

Evaluating advocacy can be difficult, and it can take years before a change is clearly visible.

It is important to be able to define and measure your success:

- How will you know when you have been successful (what change or action by the decision maker will show that your advocacy worked)?
- What will you be doing along the way that will lead to this success? How will you know when you are reaching these milestones?
- Have you set some measurable targets? These might include things like the timing of your key milestones, the number of petition signatures, number of media stories, or the number of meetings with decision-makers.
- At the end of the campaign, it is important to hold a debrief and evaluation session where you can reflect on what went well in your advocacy, and what could be improved for the future. If the advocacy involved a coalition or consumers, involve them in some way in the evaluation.

Stroke care in Brazil has evolved over the last decade. Following years of advocacy efforts by the Brazilian Cerebrovascular Diseases Society and the Brazilian Academy of Neurology, in 2012, the Brazilian Ministry of Health published the National Stroke Policy Act, finally setting the battle against stroke as a national priority. Since then, major steps have been gradually implemented to improve stroke care in the country.



CASE STUDY

World Stroke Day in 2012 and the presence of the World Stroke Congress in Brazil helped bring substantial media exposure to the condition, with strong support by the Brazilian Ministry of Health.

In the 14-month period following the 2012 World Stroke Congress, 32 new stroke units were opened in Brazil, with more scheduled to open. In those regions where stroke units were introduced, the improvement in stroke care is impressive - a reduction of 12% in the death rate caused by stroke.

You might also need to consider how successful the goal you chose is in solving the problem you are addressing. This is different to evaluating how successful your advocacy plan is.

For example, if you chose a goal of securing funding for a FAST Campaign from your local government, the success of your Advocacy Plan is FAST funding secured. But the success of the FAST Campaign itself would be increasing numbers of people knowing the signs of stroke, more people arriving early to hospital.

This step is about the success of your Advocacy Campaign and might include things like

1. Number of partners in advocacy efforts signed up
2. number of meetings with potential advocacy partners
3. Number of meetings with key decision maker
4. Number of grass roots supporters signed up and active

There are more examples of advocacy measures in the table below. Your measures would need to be tied to your own plan, and to consider the steps you identified in Step 8 that will help you achieve your goal.

MONITORING AS YOU GO

Evaluating the progress and effectiveness of advocacy efforts requires regular monitoring.

Use the timeline you developed in Step 8 to monitor progress with your advocacy efforts. Check in to make sure you are achieving what you wanted to when you wanted to. You may need to readjust your timelines as you go.

You should hold regular campaign progress check meetings. This is a chance to check if you are meeting your targets, whether you are moving towards your goal, and whether you need to change anything to take into account new opportunities or problems.

If your advocacy involves working in partnership with others, it will be important to include your partners and allies in regular reviews. Part of these regular reviews should also involve checking on the partnership itself.



Monitoring milestones

One of the best ways to monitor progress on your plans is to use the map of the key milestones to monitor the timing of delivery you developed in Step 8, to tick off your milestones when they are achieved. This can also help inform others if you are working in partnership.

Measuring progress

Monitoring progress can be done through simple measures that tell you how effective aspects of your campaign are. You need to think about how you will collect this information if you are going to do it. **Some examples of measures are in Table 9.1**

Table 9.1. Examples of potential measures to collect:

Digital / social media (email, websites, blogs, podcasts, texts, Facebook, Twitter)	<ul style="list-style-type: none"> - New website developed - # of messages sent - Frequency of messages sent - # of subscribers
Earned (free) media (pitching to print, broadcast, digital media)	<ul style="list-style-type: none"> - # of outreach attempts to reporters - # Press releases developed & distributed - Number of mentions in the media
Coalition and network building	<ul style="list-style-type: none"> - Number of coalition members - Types of constituencies represented in the coalition - Number of coalition meetings held and attendance
Grass-roots organizing and mobilization	<ul style="list-style-type: none"> - Number of people who have signed up to the campaign - Number of people who are active in promoting campaign - Number and geographical location of communities where organizing efforts take place - Number of community events or trainings held and attendance
Briefings/ presentations	<ul style="list-style-type: none"> - Number of briefings or presentations held - Types of audiences reached through briefings or presentations - Number of individuals attending briefings and presentations
Polling	<ul style="list-style-type: none"> - Polls conducted with advocacy audience(s)



There are some online resources to help you evaluate your success.

These include

1. SurveyMonkey: a free online survey tool you can use to survey partners about satisfaction with the campaign, poll members of your grassroots campaign, even poll people to build a case for your goal. <https://www.surveymonkey.com>
2. Google Analytics: <https://analytics.google.com>
3. Facebook Analytics <https://analytics.facebook.com/>
4. Twitter Analytics <https://analytics.twitter.com>
5. Hootsuite <https://hootsuite.com/>

Monitoring and evaluation challenges

Remember

- Time frames can be unpredictable.
- Strategies and milestones shift.
- Assessing progress is important, not just impact. Just because a advocacy goal was not achieved in the anticipated time frame, it doesn't mean failure.
- Some contexts for implementing advocacy strategies are more complex than others.

Next Steps...

Now that you have worked through the nine steps and shaped your advocacy strategy, it is time to start putting things into action.

EXTENDED CASE STUDY

Heart and Stroke Foundation of Canada: Working with partners and government to building the Ontario Stroke System



CASE STUDY

Ontario is the most populous of the ten Canadian provinces with 13.6 million residents, and includes the biggest city (Toronto) as well as the nation's capital (Ottawa). It is often called the most culturally diverse city in the world, with half of its population born outside the country.

7

In the mid 1990s stroke was described as Canada's most forgotten disease, and viewed as a hopeless condition. Stroke care across the country, including in Ontario was lacking: only 4% of acute hospitals had dedicated stroke units, and only 24% had emergency room stroke protocols in place. Thanks to a coalition of tireless stroke advocates, led by the Heart and Stroke Foundation, the Ontario government formalized and funded the Ontario Stroke Strategy in 2001. This groundbreaking strategy re-organized stroke care across the province to ensure all Ontarians had access to appropriate, quality stroke care in a timely manner.

“This is multifactorial to be sure, but I suspect that some credit for these impressive statistics can be attributed to the efforts of the Heart and Stroke Foundation and the Ontario Stroke Network/Ontario Stroke System with the set-up of prevention clinics, acute stroke protocols, development of stroke units, and ongoing efforts for rehabilitation and reintegration along the continuum of care.”

Dr Sandra Black, Commenting on a published paper that revealed a 32.4 % decrease in stroke incidence rates in Ontario between 2002 and 2013.

Where we started

Health care providers, led by several champions, approached the Heart and Stroke Foundation and asked it to do for stroke what it had already done for cardiac care. These professionals wanted Ontarians to understand what stroke was and that it was a medical emergency, and they wanted the system in place to provide effective and timely care. Around that time, the clot-busting drug tPA, was approved for use in Canada for ischemic stroke, further highlighting the importance of putting into place systems for people to access acute stroke treatments more quickly.

What needed to be done:

- **Build public awareness.** Raise awareness among the public to recognize the signs of stroke and understand it is a medical emergency.
- **Improve systems and services.** Enhance professional education and implement system changes across the continuum to improve stroke care.
- **Obtain funding and support.** Convince the government that investing in stroke care would measurably improve the health of Ontarians.

Cont..... Building a coalition

Many players needed to be involved including hospitals, the health care system, health care providers, and stroke survivors and caregivers in order to convince government of the importance of investing in system changes for stroke care.



CASE STUDY

Four hospitals showed leadership by testing a model of regional coordinated stroke care. These demonstration sites agreed to make changes and invest in three-year pilots as part of the Coordinated Stroke Strategy. The Foundation facilitated the projects and helped them learn from each other. These pilots were critical; they built credibility by demonstrating success. For example, one site ran a public awareness campaign and implemented a bypass protocol which resulted in 12% of stroke patients receiving tPA. This was significantly higher than other areas in Canada and the US.

Many stroke leaders made a huge commitment of time and leadership, providing credibility and participating in working groups and panels. They helped perform an audit of existing services, trained colleagues and new stroke professionals, participated in meetings with the government, provided expertise in areas such as rehabilitation, and participated on the steering committee that oversaw the development of the pilot projects.

Stroke survivors and their caregivers advocated and shared their personal stories.

Working in partnership with government

The Foundation faced several challenges to convincing the Ontario Government to implement and fund a stroke strategy. The Foundation did not have a stroke working relationship with the government at the time; the government had many other health care priorities; and stroke care could not be positioned as an “ask”, it had to be a “win” for government.

Foundation staff met with government officials, including the Minister of Health, and Foundation volunteers (many of whom were stroke survivors) met with their local members of parliament (again including the Minister of Health). Key bureaucrats were involved in all working groups and panels and became important champions. They provided advice on how to fit a stroke strategy within the Ministry’s policies and priorities and how to speak its language. They became strong advocates and helped build commitment and ownership within the government.

Two well known and high profile stroke survivors (a former high ranking politician and a well known business man) spoke at a key event attended by important government officials.

Factors for success

This model has been adapted and built on in provinces across the country resulting in a Canada-wide stroke strategy.

The success of the Ontario Stroke Strategy was due to a combination of:

- *strategic decisions*
- *best use of scientific evidence*
- *identifying champions and involving a variety of stakeholders*
- *building a case and demonstrating what success looks like*
- *telling the right stories in the right language to the right people*
- *hard work and perseverance*
- *good timing*
- *luck.*

GLOSSARY

Advocacy - activities that bring about change in policies, practices and attitudes of organizations and institutions about stroke.

Campaign - Goal-oriented attempts to inform, persuade, or motivate behaviour change in a well-defined audience.

Collaboration - A recognized relationship between part or parts of different sectors of society which has been formed to take action on an issue to achieve outcomes which is more effective, efficient or sustainable than might be achieved by acting alone.

Evaluation - A systematic process that records and analyzes what was done in a program or intervention, to whom, and how, and what short- and long-term behavioral effects or 54 outcomes were experienced. Types of evaluation include exposure, formative, implementation, and outcome evaluation

Lobbying - a targeted activity and is mainly consisting of a direct influence on decision-making persons.

Outcome - A change in an individual, group or population which is attributable to a planned intervention or series of interventions, regardless of whether such an intervention was intended to change health status

Partnerships – A voluntary or formal agreement between two or more partners to work cooperatively towards a set of shared outcomes.

Policy - A plan, course of action, or set of regulations adopted by government, businesses, or other institutions designed to influence and determine decisions or procedures

Policymaker - typically government officials or those with formal political power, but they also can be leaders in the private sector whose decisions and behavior affect communities.

Target audience - The person or people to whom an organization is advocating or trying to address through their organizing campaign.

About the World Stroke Organization

Our vision: A life free of stroke.

Our mission: The World Stroke Organization's mission is to reduce the global impact of stroke through prevention, treatment and long-term care. We work to reduce the impact of stroke on individuals, their families, and their communities. Our members campaign together to increase awareness of stroke risk and to improve treatment and care. We believe that reducing the global burden of stroke makes the world a healthier place for everyone.

World Stroke Day: Established by the World Stroke Organization in 2006, World Stroke Day is observed worldwide on October 29 to underscore the serious nature and high rates of stroke, raise awareness of the prevention and treatment of the condition, and ensure better care and support for survivors.



Corporate partners

The World Stroke Campaign has been made possible through the generous financial contribution of its corporate partners.



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one voice
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