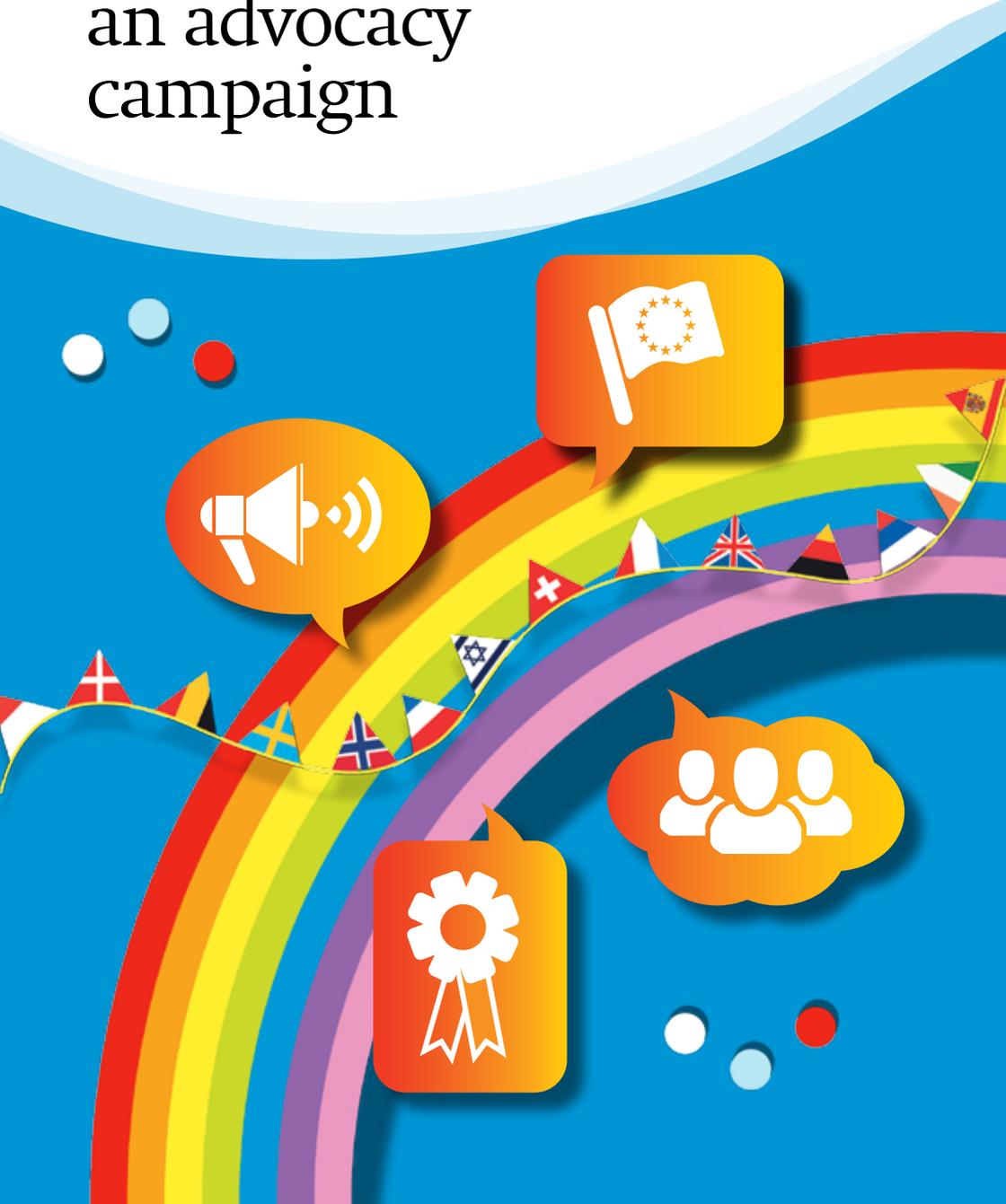


EPDA guide to Developing an advocacy campaign



EPDA GUIDE TO... DEVELOPING AN ADVOCACY CAMPAIGN

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WELCOME

Welcome to the EPDA's guide to developing an advocacy campaign. We know that many of our members face numerous and complicated challenges when initiating a dialogue with their key stakeholders. As a result, this booklet takes a very simple approach to engaging with these individuals and institutions – while providing guidance on how to initiate activities that raise awareness of Parkinson's in your country. The overall objective of this guide is to give you the confidence to help shape your national health agenda and to promote the interests of your members – the people with Parkinson's themselves.

You can start using this guide immediately. But don't forget: your advocacy campaign must complement your work with the media and other allies/associates such as the industry, healthcare professionals and funding institutes. We urge you to use this booklet in conjunction with the other guides that are currently in our toolkit series. For more information about the guides – which focus on fundraising, working with the media and social media, and working with the industry – visit www.epda.eu.com.

We sincerely hope that this booklet helps you to co-ordinate advocacy efforts across Europe, thereby reducing the inequalities that currently exist. This, in turn, will facilitate the exchange of best practice between national organisations and lead to a better quality of life for people with Parkinson's everywhere. Good luck!



Knut-Johan Onarheim
EPDA President

INTRODUCTION

WHAT IS ‘ADVOCACY’?

Advocacy – or lobbying – is a way you can make the voice of people with Parkinson’s heard. It helps to increase the power and influence of your organisation and to make policymakers aware of unmet needs. It could be a campaign raising awareness of the need for greater support for carers; or more Parkinson’s nurses; it could be lobbying for a certain drug or treatment to be fully reimbursed; or a campaign to amend legislation under discussion in your national parliament.

It is your way to make an impact. Advocacy is about making a change for the people you represent.

The key to a successful advocacy campaign is to gather widespread national and regional support. This can be achieved through building coalitions, collaborating with other organisations, encouraging community activity, fundraising, lobbying, and liaising with the media.

WHAT DOES THIS GUIDE DO?

This toolkit has been created as a step-by-step guide to planning, preparing and initiating your advocacy campaign. You can adapt the guidance and the tools according to your needs and ask the EPDA for support when developing your campaign.

This guide will help you to:

- understand the European political arena
- engage with key players and advocates who could support and champion your work programmes
- create messages that can help you to successfully influence national policy and legislation

- adapt and use materials (such as letters, press releases and presentations) to support your advocacy campaigns.

WHO IS THIS GUIDE AIMED AT?

This toolkit has been designed to help national Parkinson’s organisations gather the confidence to support the public affairs and policy work that the EPDA is involved with at a European level. Because organisations such as yours can play instrumental roles in an effective Europe-wide lobbying campaign, your objectives will be closely tied to those of the EPDA.

THE 10-STEP APPROACH

This guide is divided into 10 steps, each of which is a building block to help you construct a long-term advocacy campaign. Taking a step-by-step approach will allow you to tackle each component separately and adapt the tools at your disposal to mirror the cultural and political nuances of your country.

Bear in mind that although each step builds on the previous one, the chapters are structured to offer quick and easy reference points without you having to read the entire toolkit. It is just as useful for those at the beginning of their advocacy activities as it is for those with existing networks.

It is a good idea to take a break after you have read each stage and then revisit it at a later time to see how you could strengthen your plans further. It is also important to remember that all of your work can be reused as you develop your strategies. This will help deliver short- and long-term goals, assist your work with the media and the industry, and your other fundraising activities.

At the back of this book, you will find a

selection of appendices that provide further information – including useful case studies of how patient organisations with limited resources such as yours have already effectively raised awareness among government officials and influenced government policy.

DON'T FORGET...

When using the toolkit you think about:

- how the guidance and documents provided in this booklet can be adapted to your national situation
- the importance of complementing the content with additional national or regional information, data and statistics
- how you can set achievable goals over a period of time.

By being proactive about how you can make the most of the above points, you will automatically be strengthening your outreach and potential alliances with policymakers and third parties.

“
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”

A GUIDE TO PUBLIC AFFAIRS IN EUROPE

WHAT IS 'PUBLIC AFFAIRS'?

'Public affairs' is about influencing people in power and shaping policy. It is central to the democratic decision-making process, and its main aims are to influence public policy, and find a common ground with a wide selection of people.

For you and your national Parkinson's organisations to make an impact on policy, you will need to communicate effectively not only with politicians and officials in Parliament, but central and local government representatives, and pressure groups and political parties too. There are many and varied entry points into the policymaking process.

WHAT IS 'POLICY'?

'Policy' can be defined as a plan of action that is adopted by a person or organisation. Policy exists at many levels – here we will deal mainly with national and regional levels, and look at how that feeds in to the European level. Your goal is to increase your ability to participate in the formation and development of policies so that your objectives are met.

Efforts at a local level are interlinked with efforts at the national level, in the same way that national level efforts are linked to the European level. Starting locally provides a base for work at the national level. Likewise, advocacy campaigns at a European level may affect policies at a national level, which will

then be filtered down to the local level. In short, there are numerous links between local and national organisations' agendas and those of the European Union.

The best kinds of advocacy campaigns not only meet short-term goals but also build a strong sense of community, raise awareness, build alliances, engage policymakers and work towards shaping national and European views.

DIFFERENCES IN POLITICAL CULTURES ACROSS EUROPE

Public health ranks highly on the political agenda in the majority of countries and regions. Policymakers are acutely aware of the costs of an ageing population and the increasing number of people in need of care, technological innovation, consumer expectations, and more vocal patients.

In addition, an increasing number of patient organisations are becoming more active in advocating their demands to policymakers. These developments have contributed to an increased and growing pressure on health systems and budgets.

Highlighted below are some examples of key characteristics for engagement in Europe.

Western and Northern Europe

Advocacy is an important part of the decision-making process in Western Europe. NGOs, patient organisations and other groups provide solutions and expertise, and give legitimacy to political decisions. As a result, policymakers and politicians in this region are aware of – and are accessible to – advocacy groups. The general trends are as follows:

- Policymakers are open to solutions.
- There is an increased dialogue between stakeholders such as NGOs, research

- institutes, think tanks and industry.
- Building partnerships and ‘working together’ is seen as very important now.
 - Ethics, transparency and accountability are important to politicians.

Southern Europe

Policymakers in Portugal, Spain and Italy view advocacy as an important part of the democratic process; however, there are concerns in some countries, especially in Greece, that it favours the wealthy and elite. The general trends are as follows:

- Ethics, transparency and accountability are major concerns for policymakers. They are worried that undue influence is being exerted by organisations (including non-governmental organisations) that aren’t transparent and accountable.
- The provision of biased information is seen as a problem by Italian policymakers.

Central and Eastern European Countries (CEEC)

Advocacy in CEEC is neither accepted nor understood to the same extent as in Western Europe. The region is still learning how to advocate effectively and there is a general lack of transparency and professionalism.

However, while the practice of lobbying may be in its infancy, its regulation is further advanced than in Western Europe. The Association of Professional Lobbyists in Poland, for example, formed in 2003 and created a voluntary code of self-regulation for lobbyists. Lobbyists in Lithuania and Hungary have also adopted measures on ethical advocacy, while Romania is not far behind.

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You will need to communicate effectively not only with politicians and officials in Parliament, but central and local government representatives, and pressure groups and political parties
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Overall, politics and parliaments play a more central role in post-communist nations. When engaging with politicians, the focus should be on building relationships with leaders in national governments. Moreover, NGOs are becoming more vocal and seen as a trusted source of information.

Always keep in mind the differences between political cultures across Europe as these can affect how you approach advocacy in your own country.

STEP 1

UNDERSTAND THE ISSUE

Two of the most important aspects to any successful advocacy campaign is an appreciation of the fundamental issues and concerns that people with Parkinson's face, and a basic understanding of European and national health policies. Just as importantly, you need to know how and when to use your knowledge in order to gain support from policymakers and third parties in the political arena.

AT THE NATIONAL LEVEL

Focus on gathering information and intelligence available in your country. As you develop your messages, remember to explain: what is the impact of Parkinson's on the individual and their families; how many people are affected by the disease; and what the costs to society are. This will help in producing materials, data and evidence that you can use later on in the advocacy process when you approach policymakers and third parties.

WHERE TO LOOK

Here are a few sources of information:

- people with Parkinson's in your country
- other member organisations' websites (look on the EPDA website for details)
- local, regional and national institutes and universities
- local, regional and national healthcare providers such as hospitals and health clinics

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Once you have begun collating information on Parkinson's and other related policy issues at a national level, you will have gained a better understanding of the current policy environment
”

- media publications
- medical journals
- professionals and academics who specialise in Parkinson's
- current national policies and plans.

Once you have begun collating information on Parkinson's and other related policy issues at a national level, you will have gained a better understanding of the current policy environment. The next step is to define your objectives.

TIP

Remember to keep a record of your research and sources of information. It is important to build an accurate and detailed body of information, data and statistics that you can use later in your advocacy campaign and refer back to frequently.

STEP 2

DEFINE YOUR OBJECTIVES

You must clearly define the objectives of your advocacy campaign. These can vary from raising awareness and influencing national health policies, to applying for funding. They can be highly detailed (for example, a targeted lobbying campaign to amend legislation under discussion in your national parliament) or more general (such as raising awareness of the need for greater support to carers in the community).

CONSIDER WIDER OBJECTIVES

To have a successful national strategy it is important to keep in mind the EPDA's wider European objectives. Linking our messages across Europe will help build strong campaigns at the national level. The box on the right offers some suggestions of broad objectives you can adapt – however, remember that you will need to tailor the tactics to your own specific situation and needs.

ASK DIFFICULT QUESTIONS

From the outset, you must ask yourself this important question: “What do we want to achieve from our advocacy campaign?” Considering the question at the beginning of the process will allow you to develop a plan that can be measured and analysed (see page 28). If you wait until the end of the campaign before you consider measurement, all your hard work could have been in vain.

CONSIDER YOUR OVERALL OBJECTIVES AND OUTCOMES

Set out five to 10 key objectives that you feel your organisation can achieve in your chosen timeframe. Here are a few examples:

Key objectives

- 1** Raise awareness of the challenges people with Parkinson's face and highlight solutions to these challenges in your respective public and policy forums.
- 2** Ensure that Parkinson's and other neurodegenerative diseases are included in national health objectives.
- 3** Identify key areas where national policy can be improved, and then educate and influence policymakers.
- 4** Increase the minimum standards of support, treatments and standards of care provided to people with Parkinson's and their carers.
- 5** Secure resources and funding by organising fundraising events and/or approaching third parties.

Don't forget...

...to keep in mind the following questions:

- How can you link your objectives to the work you do with other allies such as the EPDA and the media?
- Can your fundraising efforts help deliver these goals or can you use your advocacy campaign to help raise funds?
- How can you keep your objectives flexible so they can manoeuvre around obstacles?
- How can your objectives be used with other advocacy campaigns, for example around disability, carers or reimbursement?
- Think about the successful outcomes you want to achieve. These will help to define your objectives.

STEP 3

KNOW YOUR AUDIENCE

Once you have defined your objectives and you know whether to raise awareness or to secure funding, you must outline your audience base. In simple terms, this can be split into policymakers and non-policymakers (such as media representatives, academics, medical experts, think tanks, other patient groups etc). All these groups are interlinked and have an important part to play in building a successful national campaign.

The following questions can help you determine who to include in your audience base. Remember, however: before you target people, find out about them first (see box on page 14).

Policymakers

- Who is responsible for healthcare in your country's government?
- Who decides public spending?
- Who is the key person behind the decision making? What do you know about them?
- What are the national health priorities?
- How can potential government projects include your objectives?
- What should the law include instead?

Non-policymakers

- Who are the leading academics in your field?
- Who are the leading medical experts with an interest in Parkinson's and neurodegenerative diseases?

- Are there any other patient organisations with similar messages?
- What is the leading medical journal?
- Who are the key health journalists?
- Has Parkinson's been covered in the press and the media?

MAKING CONNECTIONS

Carrying out a mapping exercise will help you understand your audience. The aim of mapping politicians, government officials, media representatives or academics is to identify the main people working on your key issues. So, how do you find your key contacts? Here are five essential ways.

1 Research key people who have been involved with Parkinson's and neurodegenerative diseases in your country.

2 Examine the project leaders in university research projects.

3 Read national health publications and medical journals.

4 Research other successful patient organisations and the work they do.

5 Attend university debates, medical seminars and public hearings to get a thorough understanding of the key people you would like to be on your side. Informal meetings are a great way to make initial connections and to profile your organisation.

POLICYMAKERS

Identifying relevant political policymakers

The object of mapping or undertaking an audit of politicians and government officials is to identify the main actors on

issues of key relevance to Parkinson's and – through an analysis of their positions and influence – identify potential allies.

Understanding who is important and influential to you will allow you to prioritise your target audience. Knowing an identified politician's or government official's position on relevant issues of concern will enable you to communicate in a more persuasive manner.

Selecting politicians and other government officials

The starting point for the selection of stakeholders should be a focus on the issues of importance to you as an organisation that represents the concerns of people with Parkinson's in your country.

Once you have established the key issues, politicians and government officials of potential relevance on these issues should be selected. As the institutional set up and distribution of competencies vary from country to country, you should identify the officials that are most relevant with regard to a specific issue. For example, in Germany, certain competencies sit with the regional authorities rather than with the Federal authority. Relevant decision makers could include:

- members of national or regional parliaments who sit in the relevant parliamentary committees that deal with health policy or social issues, such as care for the elderly (e.g. Committee on Public Health)
 - government officials in ministries and, more specifically, in departments that are responsible for relevant issues (e.g. Ministry for Health and Social Affairs).
- The relevance of a politician and

DO SOME HOMEWORK ABOUT YOUR 'TARGETS'

The more information you have about your target audience, the easier and more efficient your task will be. You can find out a large amount of information about people by following these suggestions:

- Look at the organisational chart of the health-related body in question to see who is heading or sitting within the departments that are relevant to you (such as a ministry or a specific parliamentary committee)
- Research his or her name and interests on the internet
- Examine a decision maker's public communication such as speeches, press releases, memoranda or other documents. In addition, you could search their personal websites to see if they have participated in any relevant events
- Examine their political party's health and funding objectives
- Ask a friend, colleague or a medical expert if they have any information about your target audience. Use your own connections as this will help you to develop your own relationships
- Use your local government branches to gather information on national politicians
- Gather intelligence through trusted third parties/experts.

Researching your target audience may take time but be sure to keep all information you come across. It will help you build a picture of the political landscape and the people you need to approach as part of your strategy. You will also come across policymakers that may not be high in your priority list but can become relevant at a later stage.

government official should be determined in the following ways:

- 1 The power of the decision maker:** identify policymakers who can influence and/or make real decisions in your areas of interest.
- 2 Interest:** do they have a keen political interest in the issues that affect you?
- 3 Their political agenda:** research their political party's objectives – find out where your interests overlap.
- 4 Their approachability:** identify policymakers who are active with non-governmental organisations.
- 5 Geographical relevance:** remember the saying that 'all politics is local politics'. The constituency element is often important especially when engaging with politicians. For the first round of engagement, prioritise those who are from the same locality as you. Being able to position yourself as a voter will make the decision maker more approachable and receptive to your messages and concerns (see box on page 13).
- 6 Their background:** be sure to research your policymaker's background – you may find information on health issues they are interested in due to personal experiences with Parkinson's.

TIP

The importance of less-senior officials or policy advisers to politicians or ministers should not be underestimated when determining the relevance of a decision maker.

“
Identifying an official's position on relevant issues of concern will enable you to communicate in a more targeted and persuasive manner
”

Within governmental ministries, the respective minister will establish the political guidelines and priorities, but in most cases it is a specific desk officer (civil servant or bureaucrat) who will be the expert on an issue and therefore be in a position to considerably influence the overall position of the ministry. They will also work on the details of a legislative proposal or a policy initiative. The same holds true for parliamentarians whose positions on specific issues are strongly influenced and shaped by their policy advisers.

But what if you can't access the right people? Can a local politician help? In most countries it is surprisingly easy to have a meeting with your local member of parliament – after all they need your vote to get re-elected. As a result, they may be willing to meet you, and you may learn some useful information that is of interest to you, such as their views on caring for the elderly or their priorities for funding research.

A politician may even agree to speak at

a public meeting or event you are organising. Remember that favourable publicity is always interesting to policymakers so make it clear to them if a photographer and journalist will be there.

NON-POLICYMAKERS

To have a successful national campaign it is imperative that you focus on extending your audience base beyond policymakers and government officials. There is a vast expanse of knowledge and expertise in your country to help your campaign.

The media

The media is a very important industry as it holds a powerful sway over national governments. It can also influence the electorate, report on government affairs and is interested in political decisions and policy objectives. In order to catch the interest of both the policymaker and the press, it is necessary to build a relationship with your national and/or regional media.

For more detailed information, download the EPDA's 'Guide to working with the media' at www.epda.eu.com/toolkits.

Other third parties

You should also try to involve doctors, academics and university professors in your advocacy plans. These non-governmental figures can often be seen speaking at political conferences, attending public hearings and adding to national debates. Unlike policymakers, academics and medical experts may be more accessible and they can often have more empathy for your cause.

In addition, strongly consider linking with other umbrella patient

HOW TO CONTACT YOUR LOCAL MP

You can use an internet search engine to find your MP's personal website. From here you will be able to find their local/constituency address. Local authority websites may also have contact details of MPs in their area and will have details of which MP covers which area.

It is better to contact MPs via their constituency office rather than in Parliament itself. By doing this, you are more likely to speak to an assistant who will be able to help straight away. This also allows you to build a relationship between your organisation and the MP's constituency staff, which can have advantages for future requests for meetings or invitations to events.

In presenting a case to an MP:

- explain clearly and straight away why you are writing and what concerns you have
- be factually correct. Ensure that everything you say can be backed up with evidence
- keep the letter concise. Two pages should be the absolute maximum, and in most cases you should aim to complete the correspondence on one side of A4 paper
- never use standard or photocopied letters. A personal approach is vital
- show that you expect a reply and ask your MP action something. This could be to:
 - » agree to a face-to-face meeting to discuss your issues
 - » raise your issue in Parliament
 - » publicise your issue in the local press
 - » attend your event or make a visit to your organisation
 - » write to the Minister to ask them to take action.

See pages 20-23 for more information about engaging with policymakers.

organisations in your country that advocate for patient rights and/or disability rights. These groups can be highly effective in building a strong campaign and influencing policymakers.

By joining forces with other patient groups, you will your voice louder. The EPDA, for example, works closely and effectively with other European umbrella organisations including Alzheimer Europe and the European Multiple Sclerosis Platform to organise meetings and lobby in the European Parliament. This is because many of the EPDA's aims are similar to its partners – it is only the disease area that differs.

EVALUATE A DECISION MAKER'S POSITION AND INFLUENCE

An assessment should be carried out for each decision maker you identify. Don't forget to include their likely position towards your organisation and your respective key issues as well as their ability to influence relevant audiences.

While this can take time, a wealth of information can be found on the internet, which is a good place to start the research process. Many political figures will have their own websites that can tell you about their interests. Through this research, you can start to build a picture of the individual.

HOW THE EPDA EVALUATED A STAKEHOLDER'S INFLUENCE				
Name and contact details	Relevance	Attitude towards Parkinson's	Positioning and influence	Engagement record
<p>Ms Maria Iglesia Gomez</p> <p>Address: European Commission, DG Health and Consumers, B-1049 Brussels, Belgium</p> <p>Tel: +32 (0)2 2953036</p> <p>Email: maria.iglesia-gomez@ec.europa.eu</p>	<p>She is an influential European Commission official: DG Health & Consumers, Head of Unit-Unit D1 Strategy and International.</p> <ul style="list-style-type: none"> • Before coming to Brussels she worked at the Public Health Department of the Ministry of Health and Consumers in Madrid. • Her team is responsible for developing strategies for Innovation for Health and Consumers. • One of the current projects is to set up the process to launch the Innovation Partnership on Active and Healthy Ageing. 	<p>Evaluation: 4 out of 5 (positive)</p>	<p>General public/media: 3 out of 5 (influential)</p> <p>Policymakers/governments 4 out of 5 (very influential)</p> <p>Healthcare community 4 out of 5 (very influential)</p> <p>Patients 3 out of 5 (influential)</p> <p>OVERALL EVALUATION: 4 out of 5 (very influential)</p>	<p>High priority</p> <p>Meet with Ms Gomez to highlight the EPDA launch of <i>The European Parkinson's Disease Standards of Care Consensus Statement</i> on 22 November 2011.</p> <p>Ongoing communication to highlight Parkinson's in the EU's Active and Health Ageing Innovation Partnership.</p>

The table above is an actual EPDA example from 2011 – specifically developed prior to the launch of *The European Parkinson's Disease Standards of Care Consensus Statement* in the European Parliament.

Position

A politician or government official's view towards an organisation that champions people with Parkinson's can be gleaned from their speeches, press releases, questions asked in parliament, motions raised etc.

For policymakers, however, the analysis of their positions on specific issues should not only be based on their own activities and comments but also on the activities undertaken in the name of the ministry or policy institution they work for, such as their political party. These can include party electoral programmes and speeches at party conferences.

Influence

After the assessment of the politicians' and government officials' attitude and their ability to influence the general public's opinion, their influence needs to be addressed. This can be challenging because information about their influence cannot always be derived directly from publicly available information – it will require a certain understanding of the political and societal context.

Other factors to take into consideration include the size and influence of their organisation (government department or political party) and evidence of past instances in which they successfully influenced policy decisions or helped to raise the profile of an issue by gaining wider political or media support. It can also be helpful to look at the media and instances where the individual may have been quoted in the press, as this indicates a certain degree of influence.

PRIORITISING STAKEHOLDERS FOR ENGAGEMENT

The outcome of your assessment of a person's position, attitude and influence will allow you to determine their priority levels, willingness to engage and means of engagement. The table on page 14 (opposite) should help you to prioritise your partners on the basis of their attitude and influence ratings. This will help you to strategically select who you wish to become your priority targets for engagement.

TIP

When selecting your target audience for actual engagement, you might also want to consider the following criteria:

- **Approachability:** start your engagement with those who are more approachable. Who is open for a dialogue with your organisation?
- **Geographical relevance:** the constituency element is often important – especially when engaging with politicians. For the initial engagement attempt, you could prioritise individuals in constituencies where your or your office is based. This isn't always possible but being able to position yourself as a constituent will make the targeted decision maker much more receptive to your approach.

STEP 4

DEVELOP YOUR KEY MESSAGES

Your engagement strategy must have the right messages in place. Politicians and policymakers have often heard disease-related problems before, so it is your role to provide them with solutions. Building on your growing network with third parties (such as medical experts and academics), you can construct messages that will attract policymakers' attentions and influence them to change.

DEVELOPING KEY MESSAGES

To succeed in any engagement strategy, it is important to get the right messages to the right audience at the right time. Start with considering the concerns that people with Parkinson's and their families face. Remember, though, it is not enough to simply say that things are bad for people with Parkinson's – you need to provide solutions too. It is essential you carefully craft your messages and communicate your key objectives.

Note that every target audience has its own wants and needs. Here are some examples of their needs:

- **MPs:** local constituency issues, personal interests, favourable publicity, fairness, career progression
- **Civil servants:** problem solving, efficiency, reducing workload, data/information
- **Ministers:** political narrative, national constituency, party considerations,

evidence-based facts and figures, favourable publicity

- **Opposition:** headlines, scrutiny, policy changes
- **Patient groups:** public awareness, patient outcomes, funding
- **Clinicians:** outcomes, funding, autonomy, empowerment

Once you have shaped your messages, they will form the basis for a dialogue with your targets and be vital in extending your communications and media strategy around your national campaign.

FACTS AND FIGURES

It is important that, where possible, your key messages are backed up by solid facts. For example, what is the impact of Parkinson's on the individual, their family and society? How many people are affected and, importantly, what are the costs of the disease? Can costs be cut by the right intervention at the right time? If you answer these questions, your message will become much more persuasive and will address the questions your audience may ask having heard your message.

MESSAGE HOUSE

The 'message house' (see table on page 17) is the architecture within which your key messages sit. In other words, it has one overarching position statement or 'mission', followed by supporting key messages that make up the three pillars of the house. Proof points do not sit within the message house, but they can be used to back up your key messages and make your communications stronger and more persuasive.

The message house delivers a 'one-stop

shop’ for key messages for a particular audience. When any communications to a target audience are being developed, the message house should be referred to – therefore ensuring your communications are in line with its content. The message house should always be reviewed when developing materials for a different target audience to ensure that the messages are still appropriate and to adapt them (and the corresponding proof points) if necessary.

Below is an example of an EPDA-

specific ‘message house’, which is likely to be relevant to all of the umbrella organisation’s stakeholders. However, message houses can be developed to focus on particular issues that need to be communicated – in which case the messages are more likely to vary for your different stakeholders.

The EPDA’s position statement: ‘We are the only European Parkinson’s disease umbrella organisation’

Key message 1: ‘Who we represent’

Our members – 45 national Parkinson’s organisations – and we advocate for the rights and needs of more than 1.2 million people living with the disease and their families

Key message 2: ‘What we do’

By working with our members – who represent the needs of individual people with Parkinson’s and their families at a national level – the EPDA intends to:

- ensure equal and timely access to prompt diagnosis and good-quality Parkinson’s care across Europe by raising standards and reducing existing inequalities
- increase public awareness of Parkinson’s as a priority health challenge
- help reduce stigma and remove discrimination against people with Parkinson’s
- support the development of national Parkinson’s organisations throughout Europe.

Key message 3: ‘Our vision’

To enable all people with Parkinson’s in Europe to live a full life while supporting the search for a cure.

In order to make our vision a reality, we are working to become the leading voice for Parkinson’s in Europe – providing innovative leadership, information and resources to national Parkinson’s organisations, European policymakers, the treatment industry, healthcare professionals and the media. In achieving these aims, we hope to raise the profile of Parkinson’s and enable people living with the disease to be treated effectively and equally throughout Europe.

This ‘message house’ uses the EPDA as an example to follow. At the top is the organisation’s “overarching position statement” followed by the three “supporting messages” that make up the three pillars of the ‘house’.

STEP 5

DEVELOP YOUR STRATEGY

Once you have completed your research and identified your key target audience, you must decide on your engagement strategy – a plan that describes how you will meet your audience base. We recommend having a two-fold approach: direct and indirect engagement.

DIRECT ENGAGEMENT

One-to-one meetings with your priority policymakers, third parties and media representatives are the most common and effective engagement tool. You will be expected to meet with many people in order to have a successful campaign.

INDIRECT ENGAGEMENT

At times, it can be difficult to organise meetings, especially with policymakers. But do not be deterred – there are other opportunities for indirect engagement:

- photo opportunities
- speaking platforms (secure speaker placement at leading events)
- alliances with other patient associations
- publishing reports
- sending out letters/briefings/press releases to your target audience
- making submissions to national projects
- attending medical workshops/university debates.

SECURE 1-TO-1 MEETINGS

Here are nine ways to secure personal appointments with your key stakeholders.

1 Form a strategy. Send an introductory email to your target audience. Follow up four to five days later with their assistant. Always be respectful and polite, and be flexible with your meeting dates. It is important to build a relationship with your key policymaker's office.

2 Be transparent and honest. Always being open about your objectives will enhance your reputation.

3 Know what you want but remember to be flexible. Be clear about your objectives and provide solutions not problems. Be realistic and practical. Always be prepared to adapt your strategy to include new developments.

4 Be prepared. Try to familiarise yourself with a politician's opinion before you communicate with them. Do not waste your time trying to convince a politician of your point of view; instead, look to identify areas where there is agreement as these will provide an opportunity for collaboration. If you try to change a politician's opinion, you are likely to put them in a defensive position, undermining the potential for constructive conversation.

5 Adapt your message and provide independent evidence. Make it personal, tailored and relevant. This is especially important when you are meeting politicians, journalists and third parties. Keep the message simple and focused (do not try to cover too many issues – focus on the most relevant ones). Remember to use your research and independent evidence. Exploit your

knowledge of EU or national policies and the work done at the EU and national level.

6 Add value. Politicians are in the business of winning votes. If you can make a politician look good to their voters this will help build a positive working relationship. Politicians like media attention, so provide them with plenty of profiling opportunities. Ask if it is OK for you to bring a photographer.

7 Don't underestimate advisers and assistants. Policy advisers are not only gatekeepers but also shapers of their politician's opinions. They are also often more accessible than politicians so if you cannot meet the minister, try to meet their adviser. Be polite as future relationships rely on a good working environment.

8 Be confident. It can be daunting approaching a policymaker but their job is to listen to you. Don't forget that your information and expertise can make you indispensable for their work.

9 Follow up. Send a follow-up 'Thank you' letter or email.

SKILLS FOR A SUCCESSFUL ENGAGEMENT STRATEGY

- Personal integrity
- Punctuality
- Strong communication and persuasive skills
- Empathy
- The ability to listen
- A basic understanding of the parliamentary system
- Strategic skill
- Believe in yourself.

TIPS

1) Know your messages and remember you are the expert in your field. It is unlikely the politician has more knowledge than you. However do not worry if they ask a question you cannot answer. Tell them you will get back with the information and make sure you do.

2) Remember that treatment industry companies spend a lot of time and resources looking for evidence to support their own therapeutic areas of interest. By developing positive relationships with these companies you could tap into their resources. You can use the EPDA's *Guide to working with the treatment industry* toolkit to help you develop these important relationships.

3) Don't forget also that there are other EPDA toolkits that you can use as part of building your engagement strategy – such as fundraising, working with the media, and working with social media. Each guide is a complementary addition to this Advocacy Toolkit and will help draw together your activities to help you reach your advocacy goals. View all the EPDA toolkits at www.epda.eu.com/toolkits.

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Be confident. Don't forget that your information and expertise can make you indispensable to policymakers' work
”

STEP 6

IDENTIFY THE TOOLS TO HELP ENGAGEMENT

The tools identified and outlined in this section provide examples of successful means for engagement with a target audience. But bear in mind the EPDA's ethical code of practice as well as any transparency rules and regulations that apply to your country or region.

EVENTS

Organising or sponsoring an event, workshop or debate has to be carefully planned and prepared. So when you begin planning, consider the following questions:

- What issue do you want to focus on?
- Is the event part of a larger strategy that will help meet your overall objectives?
- What is the best timing for the event? Are there dates in the political calendar that you could link to in order to maximise your exposure? Remember your own calendar: for example, 11 April, World Parkinson's Disease Day, is an excellent day to plan events. But ensure your target audience is available on the day – don't assume they are free.
- Who is your target audience?
- What are your key messages?
- What is your ideal outcome?
- How will you follow-up after the event?

Content events

These could be conferences, seminars or workshops where you invite an academic,

politicians and/or government officials to speak or participate in a discussion on a particular topic. While increasing the value of your own event, you would also be providing your target audience with a platform to profile themselves.

Event co-hosted with another organisation

There may be the opportunity to co-organise events with other establishments such as reputed universities, research institutes or think tanks, where there is a common interest or where the organisation in question has worked with you on a piece of research. This type of collaboration lends further credibility to your initiative and creates an opportunity to invite a politician to speak at the event.

Parliamentary events

Organising a parliamentary event enables you to reach out to more than one MP at a time. The fact that any event organised in the premises of a national Parliament needs to be officially hosted by an MP provides a special relationship-building opportunity. Although the MP is generally doing the organisers a favour by accepting to host the event, it also provides them with the opportunity to increase their profile with colleagues who share political interests.

Depending on the national political culture, two or three different event formats are usually possible: a **cocktail reception** that allows for short-term interaction with numerous contacts (this can be ideal if you are launching a booklet or the results of a survey); a **lunch/dinner (or round-table debate)** that provides the opportunity for a higher-quality engagement with a smaller number of people (as parliamentarians

will be seated around tables with patient advocates and actively engage with them for about two hours); and a **photo opportunity** (see box, right). Make sure you prepare a press release or short factsheet in advance of the photo event. Explain that you will send both to them within 24 hours – so make sure you have their email address.

Site visits

These give you (as host) the chance to engage with your guest and to educate them about your organisation while providing them with valuable insights and information. Site visits can be organised around a thematic dimension; for example, inviting MPs with a specific policy interest (such as research, health policy, chronic diseases, age-related diseases) or a geographical dimension (perhaps inviting your local MP to visit and meet their constituents with Parkinson's to discuss the issues that affect them). Again this is a good photo opportunity so make sure you invite the local press as it would help the MP increase their profile locally.

PERSONAL MEETINGS

One of the key objectives for any personal meeting is for your organisation to be viewed as an expert partner by politicians and government officials; it is also an essential aspect in building long-term relationships. A good example of success would be if a politician proactively requests your views, approaches you to contribute to draft legislation, or invites you to participate and speak at an expert hearings or workshop. For your personal meeting to be successful you must consider the following:

ORGANISING A PHOTO OPPORTUNITY

You can use an internet search engine to find your MP's personal website. From here you will be able to find their local/constituency address. Local authority websites may also have contact details of MPs in their area and will have details of which MP covers which area.



The EPDA's Pledge for Parkinson's was a successful example of how to attract politicians to support a Parkinson's-related cause.

On World Parkinson's Disease Day 2012, the EPDA had a stand in the European Parliament from 11am to pm. It was eye-catching and in a busy location. The stand was organised with the help of an influential MEP who sits on the EU health committee, and who has a special interest in Parkinson's. Throughout the day, 50 politicians came to have their photos taken signing the Pledge.

We built on this initial success by getting more MEP signatures in the following months and years. We also worked with these supportive MEPs in a number of other areas.

Pictured above: Dr Peter Liese and Linda McAvan in the European Parliament in 2012. The two MEPs are particularly interested in health, were supporting the EPDA and its Pledge for Parkinson's, and come from the two main political groups in the European Parliament.

1 Target the people who matter. Remember your political stakeholder mapping? See Step 3 on page 10 and identify a core group of 15 to 30 contacts.

2 Respect the decision making process. Lower-level officials draft legislation so contact them first. However, approaching higher-political levels will be more beneficial if there is a lack of interest in your issues, negotiation deadlocks or high political stakes.

3 Ensure your representative is comparable to your official in terms of seniority and influence. For example, the head of your organisation should meet a minister.

4 Do your homework on the official. Find out what they might expect from a meeting.

5 Ensure that you meet expectations. Give information, suggest policy change and offer networking advantages.

6 Arrange the meeting at the right time in the policy and/or regulatory procedure.

7 Maintain occasional, respectful contact even when you do not need help. If they win a prize or steer difficult legislation through parliament then send a note congratulating them.

8 Offer your assistance even when no critical issue is at stake.

9 Always leave something behind (executive summary, position paper) to remind them of your key messages.

10 Follow up with a ‘thank you’ letter and send any extra information that may be useful and relevant.

Remember that the earlier you intervene in the policy process, the more successful the end result is likely to be. Building relationships before your issue becomes urgent is important. This will mean you aren’t just turning to the official in times of crises or when you need something.

An initial introductory meeting to exchange views is beneficial for both parties. This allows you to learn what they are focusing on and to adapt your input and messages accordingly. However, there still needs to be a good reason for arranging a personal meeting with a policymaker as they usually have tight agendas. A meeting for a meeting’s sake is not advisable.

LETTERS AND EMAILS

Letters and emails are normally follow-ups from an earlier meeting, speaking opportunity or position paper. However, they are also a good way to introduce yourself to your key target. Every meeting you have and initiative(s) you organise need to be either introduced and/or followed up with a letter or email.

Consider the following recommendations for drafting letters:

- A short cover letter is almost always useful in supporting a position paper (see example on page 23).
- Transforming the position paper or its executive summary into a letter can: increase the chances of it being read; demonstrate that you consider the reader deserves special attention; and increase the chances that you will receive a positive response.

- Personalised letters should always be used when approaching high-level politicians, officials or other decision makers.
- Remember to follow up every meeting with a 'thank you' letter or email.

POSITION PAPERS

Providing policymakers and third parties with position papers and personalised briefings allows you to further explain your position and include key facts and case studies. This is important as it allows you to state your organisation's position regarding a certain issue that affects people with Parkinson's, and communicates your message in print. It can be 'left behind' in a meeting or shared with your audience at an event you organise. Here are nine tips to consider.

- 1 Keep it short** (one page is ideal), concise and ensure it includes all your messages.
- 2 Tailor your paper to your audience** – think about what is important to them and acknowledge their politics/administrative culture.
- 3 Focus** on your main two or three concerns.
- 4 Get to the point quickly** – politicians and government officials have limited time and no obligation to hear your views.
- 5 Always provide an executive summary** – especially if it is longer than two pages. You must make the content easy to read.

6 Support your arguments with relevant factual details but always remember to provide technical information and references in the appendices, not in the body of the text.

7 Be positive and constructive at all times – even when things don't well.

8 Suggest solutions as well as highlighting problems. Always try to propose positive recommendations.

9 Remember detail is important. Highlighting unknown consequences could add to your growing position as a trusted source of reliable information and advice.

Example of a short 'thank you' letter

Dear Mrs/Mr [Name here]

On behalf of [Your organisation], again many thanks for hosting last Wednesday's Parliament reception, which marked the official launch of the [your event/campaign here]. The positive feedback we have received so far underlines the quality of the event, and it goes without saying that your contribution is highly appreciated.

The event itself and its launch have naturally been our main priority for some time, and it was highly rewarding to see such a broad group of participants supporting the initiative through their presentations and their great interest in the event's outcome. It was also particularly impressive to see the consensus that action needs to be taken to ensure earlier diagnosis and better management of Parkinson's disease. We appreciate the commitment of the many participants – including your own – to support and effect change.

Again, many thanks for your support and we look forward to keeping in touch on future activities. With kind regards,

[Your name here]

STEP 7

BUILD AN ENGAGEMENT PLAN

BEFORE YOU START

remember, your engagement plan must:

- add value – by understanding your target audience’s needs
- build trust – be honest and transparent
- be consistent – ensure you maintain regular contact with your targets
- be considerate – do not overstretch the relationship
- be patient – remember your plan has a long-term vision.

THE NEED FOR A GOOD TEAM

In the planning stages of your engagement plan, you need to consider who will be involved from your organisation and what responsibilities each person will take on. Whether your team is large or small, ensure you have allocated specific tasks for each person. This is easier in a large team but in a small team it may be more challenging.

If you have a limited number of people working in your team it may be good to break down the engagement plan into different stages so your organisation engages with policymakers in a more understandable way. When organising your team’s workload, bear in mind:

- who needs to be involved?
- who will co-ordinate the campaign?
- who is responsible for each topic/issue?
- who is the key contact for each policymaker/stakeholder?

“
You must be patient.
Remember your
engagement plan has
a long-term vision
”

Prioritise the most important issues while bearing in mind your objectives. See where there is an overlap of key areas in order to streamline your engagement activities.

GOOD OPPORTUNITIES

There are many opportunities for organisations such as yours to engage with parliamentarians directly or indirectly in order to influence legislation. Here are some tips:

- When legislation is first proposed, it is important to define your objectives, map your stakeholders, identify those you wish to engage with, develop your messages and draft your position papers.
- Create opportunities to have positive meetings with parliamentarians on relevant committees and propose amendments via parliamentarians who are supportive to people with Parkinson’s in your country.
- If there is a conciliation phase, monitor how your messages or amendments are discussed in parliament and continue engaging with parliamentarians to ensure the key concerns that have not been addressed are highlighted.
- Finally, monitor the vote. If it does not go your way, continue to engage with those who have supported you while looking at other opportunities.

STEP 8

ENGAGE

Preparation is essential before any planned meetings. You will only be successful in achieving your goals if you have done your homework according to the steps outlined in this toolkit. This is particularly the case for government officials and politicians.

BEFORE ENGAGEMENT

Do your homework, be prepared and expect to:

- conduct background briefings of the official/politician you're engaging with
- know their interests and position on key issues
- show knowledge of the political and policy process
- be able to show that you know other political groups'/departments' positions
- communicate your key messages (remember the messages from your 'message house' – see page 17)
- be able to highlight how your issue impacts on people with Parkinson's (give strong examples)
- empathise, wherever possible, with local or regional perspectives (link to the parliamentarian's constituency)
- outline your recommendations for action
- explain how the politician/government official can help you
- explain how you can help in return
- follow up with case studies and research that will assist the politician/official in their work
- leave behind persuasive resources such as position papers, factsheets or case studies.

DURING ENGAGEMENT

When engaging with politicians and officials you must:

- be relevant – understand the context and timing of the meeting
- be knowledgeable – know your issue and audience
- be constructive – offer solutions, options, intelligence and support
- be respectful – build bridges, develop trust and value partnerships

And last – but definitely not least, given the importance of policy advisers in shaping their superior's opinions – do not hesitate to meet the adviser if you cannot meet the boss.

“
Preparation is essential before any planned meetings. You will only be successful in achieving your goals if you have done your homework. This is particularly the case for government officials and politicians
”

STEP 9

MAINTAIN A DIALOGUE

Maintaining a dialogue with your target audience following engagement is crucial to positioning your organisation as a trusted and reliable partner. It is not only about seeking to win short-term goals but also about creating an atmosphere of trust and confidence. It is also important to sustain the dialogue even when there is no issue at stake. For example:

- follow up meetings and events with research studies, factsheets and ‘thank you’ letters and emails
- provide your contact with new research and case studies as soon as they are available
- invite your contact to conferences, and also hold private briefings
- share information that you know is of interest to them
- proactively inform and share information and views from other stakeholders
- offer expertise and contacts from your own network.

TRACK YOUR ACTIVITIES

Maintaining the relationship with your political stakeholder is as important as initiating the relationship in the first instance. This can be managed by inviting them to events that you are organising or simply keeping them up to date on initiatives that you are involved in, whether or not you require their support.

It is useful to track engagements so you

can share results with other organisations. It can also help you to monitor the progress you have made in building a network of political support and to follow up on possible next steps. Examples of an engagement tracker and a meeting report can be found on page 27 (opposite).

DEVELOP A CONTACT LIST

For organisations where more than one person could potentially be involved in engagement and communication activities with decision makers, it is worth creating a contact list. The purpose of the list would be to avoid duplication of effort and counterproductive communication or engagement activities. You can build the list from your efforts in Step 3 (page 10).

The list should be accessible to each of your organisation’s members who are involved (or potentially involved) in engagement activities. You should also allow each of them to update the status reports after each activity – for example, a meeting with a journalist or neurologist. The list should contain the following information on each decision maker:

- contact details
- background briefs (professional/political biography, areas of interest, general attitudes)
- contact owner and activity planner within your organisation
- relationship history (overview of past meetings, including comments and outcomes).

TIP

Remember that once you have set up these instruments to keep track of policymakers and other stakeholders, you can regularly update them and re-use these materials for current and future outreach.

EXAMPLE OF AN ENGAGEMENT TRACKER

Date of meeting	Name (of the person you met)	Their position	Their organisation	Their contact details	What was discussed?	Next steps?

EXAMPLE OF A MEETING REPORT

Objective of the meeting: [Fill in details here]

Person(s) attending	
Person(s) visited	
Date/time/place	
Materials, information, documents provided	
Main points raised in the meeting	
Actions for follow up	
Other notes	

STEP 10

MEASURE YOUR SUCCESS

Evaluating the effect of your activities is extremely important in measuring their impact and improving the outcome of work that you do in the future.

EVALUATING A 1-TO-1 MEETING

When setting up and attending a meeting with a political target you should always have an agenda and an expected outcome in mind. After a meeting, consider whether you achieved the outcome you required. If not, are there any follow-up actions you can undertake to achieve your goal? Or will you have to lower your expectations with this particular target?

EVALUATING AN EVENT

If you are running an event, how many people attended or participated? Consider questionnaires to gauge what your audience thought of the event. Did they understand your key messages? Had their attitudes changed as a result of the meeting? What did they think of the presentations? Did they have any suggestions for improving the event?

EVALUATING THE CAMPAIGN

Consider the number of stakeholder engagement activities that have taken place (e.g. the number of meetings, events and correspondence), the number of political stakeholders you have met with, the impact of your engagement on decision maker attitudes, the perception

“
Keep your engagement tracker up to date when you evaluate your campaign

”

of your organisations (before and after), the impact of your activities at a political level in terms of raising awareness/ garnering support of a particular issue. Keep your engagement tracker up to date when you evaluate your campaign. Consider also these measurement levels:

Output evaluation – what has been delivered?

This basic form of evaluation is concerned with what activities took place compared with the goals and timelines established in the engagement plan.

Outtake evaluation – what impact have you had on decision-makers’ attitudes/ perceptions?

This is the impact your engagement activities have had on your target audience.

Outcome evaluation – what impact has your campaign had on your organisation?

This is the hardest element to measure, particularly if your engagement is not specifically linked to changing a piece of legislation. It may take a longer period of time (often years) before a situation changes and the impact of engagement activities becomes measurable for your organisation.

SUCCESS MEASUREMENT CHART		
	What did you set out to do?	Evidence of success?
<p>Output – what has been delivered?</p>	<ul style="list-style-type: none"> • Did you do what you set out to do in the engagement plan? • How many decision makers have you engaged with directly or indirectly? 	<ul style="list-style-type: none"> • The number of stakeholders you engaged with • The number of people who attended your conference • The level of media coverage generated before, during and after your event
<p>Outtake – what impact has your campaign had on your target audience?</p>	<ul style="list-style-type: none"> • What messages did the targeted decision makers take away from your engagement activities? Were these accurate and positive? • How far did your engagement activities affect the attitude of the targeted decision makers? • Did decision makers act in line with your objectives (for example, have they introduced amendments to draft legislation)? 	<ul style="list-style-type: none"> • Monitor and analyse decisions taken (for example, did a leading academic agree to sign your 'open letter' to the media or join your alliance? Did a policymaker agree to host an event on your behalf in the national parliament following your meeting?) • Collate statements (e.g. press releases, position papers, speeches) made by your target audience as possible evidence of changes in attitude towards people with Parkinson's
<p>Outcome – what impact has your campaign had on your organisation?</p>	<ul style="list-style-type: none"> • What is the end result of your activities? • Did you achieve your goals? • Did you change behaviour? How? • Did you create a stronger political cause for people with Parkinson's? 	<ul style="list-style-type: none"> • Has there been a change in national policy/legislation? • Is there now more support via national government policies for people with Parkinson's • Is there an overall increase in awareness of Parkinson's that can be measured over a long period in time (e.g. one to five years)?

APPENDIX 1

CHECKLIST

To ensure your advocacy campaign is a success, it is vital to plan your activities and to record details of your developments on a regular basis. As a result, we have included a helpful checklist for you to replicate and fill out. Good luck!

Step	Actions	Timing	Status
1. Understand the issue	<ul style="list-style-type: none"> Searched national databases for the latest statistics on Parkinson's Reached out to potential contacts at the local university to find the latest studies on people with Parkinson's 	Initial research completed by the end of 2013	✓
2. Define your objectives			
3. Know your audience			
4. Develop your key messages			
5. Develop your strategy			
6: Identify the tools to help engagement			
7: Build an engagement plan			
8: Engage			
9: Maintain a dialogue			
10: Measure your success			

APPENDIX 2

WORKING WITH THE INDUSTRY

It is important to remember that your national treatment companies may be able to provide your organisation with valuable support to help develop your advocacy (and other) campaigns.

Remember that treatment industry companies spend a lot of time and resources looking for evidence to support their own therapeutic areas of interest. It's therefore important to find out if your respective priorities are aligned. If they are, then you will be on the road to building trust and understanding with potential invaluable partners and supporters.

For more detailed information about how to build your relationship with these sorts of companies, download the EPDA's *Guide to working with the treatment industry* toolkit at www.epda.eu.com/toolkits (where you'll find other relevant toolkits that will help you with your advocacy campaigns).

The key points you must remember when working with the industry are to:

- retain your independence at all times
- publish all commercial support on your website and in other resources
- create a written agreement that sets out exactly what has been agreed between both parties
- try to secure funding from as many different sources as possible
- publish your accounts on your website and in your annual report in the interests of transparency.

APPENDIX 3

WORKING WITH PR AGENCIES

You can use this toolkit to build and implement an advocacy strategy at a national level without any agency support. However, you may decide to enlist the support of a national or regional public relations (PR) agency. If so, consider the following:

- Ask organisations similar to yours if they use a PR agency and which one they can recommend.
- If you ask a PR agency for support, ensure that they provide concrete examples of delivering successful outcomes to their campaigns.
- Ensure the agency gives you a list of fees and costs of their services so that you can decide which areas could benefit from their support.
- Consider using freelance PR individuals as they can often be cheaper than big agencies. Make sure you check their credibility first by asking for references and searching out comments about them on the internet.
- Discuss with the chosen PR agency how much time they can provide per week depending on your focus and budget.
- Regularly assess what is being delivered and what could be improved.
- Be clear about the terms of the contract, payment and renewal of the agreement.
- At all times, consider other agencies that may provide better assistance in helping you achieve your goals.

APPENDIX 4

FREQUENTLY ASKED QUESTIONS

When should I start developing an advocacy plan?

It is important to start developing an advocacy plan as soon as possible so that the EPDA and its members can coordinate efforts across Europe. It need not be a rapid process but rather a step-by-step plan with clear aims and objectives. Use this toolkit as a guide when starting off and refer to it regularly.

You may also find that certain elements need to be adapted or developed to tailor it to your needs at the national level. A good plan is to create a 'road map' for your organisation that is based on the 10-step long-term engagement plan. You can then adapt the timing and plot it over a period of six months to one year, taking into account key policy milestones that can help you raise your organisation's profile.

Where can I find the information, data and evidence to understand the issue?

Firstly, gather the information you already have. It may also be helpful to seek information from other sources such as:

- The EPDA website (www.epda.eu.com)
- National Parkinson's organisations in other countries
- Your national or regional government website
- Projects and studies carried out in your country
- The European Commission's website,

which has some good information on neurodegenerative diseases. Visit http://ec.europa.eu/health/major_chronic_diseases/diseases/brain_neurological/ for more details

- The World Health Organisation (www.who.int/mental_health/neurology)

How do we develop a contact 'network'?

Member organisations across Europe have variable resources when it comes to carrying out effective advocacy campaigns. However, no matter how small or large your organisation is, you can always create, build and strengthen your network through using informal channels such as family, friends, colleagues and support from your local community.

It is also helpful to use the standard letter you develop when reaching out to policymakers as a tool that can be adapted and used to introduce yourself to new stakeholders. Networks may take time to build so try and view it as an ongoing process that needs to be maintained and developed over a period of time.

How do we create trust with policymakers?

With ethical lobbying and advocacy at the top of most national governments' agendas it will enhance your credibility and level of trust if you develop a 'Code of Practice' and ensure it is visible when reaching out to policymakers. Either place it on your website or keep it in electronic format so you can include it when contacting the policymaker. This will ensure transparency and demonstrate that the information you provide is not misleading. You can develop a 'Code of Practice' by adapting the EPDA's code, which is available at: www.epda.eu.com/about-us/partners-sponsors/code-of-practice.

How can we identify other stakeholders that can support our organisation?

To be able to strengthen your position and show that you know your area well, it is good to connect and build relations with other third parties and non-governmental organisations that can support your efforts. Patient organisations that represent people with other neurological disorders are a good place to start. Your national institute for neurological diseases (details can be found via internet search engines) can be helpful in bringing together patient organisations that share some common goals and identify avenues for leveraging support.

What happens when our targeted policymaker leaves their position?

Having successfully identified the right policymaker to influence, it can be discouraging when a person leaves their position and you need to build a relationship with their replacement. However, this could be an opportunity to highlight your issues to a new audience.

The incoming policymaker might also have past experience that could be useful when putting forward your case. It is important to find information on the new person and identify gaps you can address.

For example, the new policymaker may have been working on issues such as health inequalities in their previous position and therefore have little knowledge of Parkinson's or the challenges facing people who live with the condition.

Alternatively, a new policymaker may have had personal experiences of Parkinson's and could therefore be interested in the issue on a significant level. In any of these scenarios, a change

in the individual who covers your policy area can provide the opportunity to position your national organisation not only as a 'voice' for people with Parkinson's but also as a source of information, data and materials – therefore making you a potential influencer in the policymaking process.

What happens when there is a shift in the policy landscape?

Advocacy requires constant re-evaluation. When there is a considerable shift in the policy landscape – for example, due to a change in government or new policy measures that affect the national healthcare system – you should reassess your advocacy plan. This may take some time and you may also find that many of the basic steps and tools can be adapted to take into account the new context.

But remember that a shift in the landscape may be a blessing in disguise and offer new opportunities to build support. In these situations it is best to take your current advocacy plan and identify the key sections that need to be adapted to the new landscape. For example, you may need to remap your priority stakeholders.

Where can I get more help in undertaking an advocacy programme?

One of the crucial points to remember when developing and rolling out your advocacy campaign is that other member organisations in other European countries may have information and experience that can help you. The EPDA provides support for its members by acting as a forum for them to exchange best practices. If you need help or guidance please contact info@epda.eu.com.

APPENDIX 5

GLOSSARY OF ADVOCACY TERMS

Accountability: Accountability in the political arena and in advocacy is the accountability of the government, civil servants and politicians to the public and to legislative bodies such as a congress or a parliament.

Advocacy: Taking actions to help people say what they want, secure their rights, represent their interests and obtain services they need.

Audience: A group of people that can serve as spectators or listeners to the issues you want to raise, and may be possible to influence (e.g. decision makers, journalists and other patient organisations).

Briefing: A document that provides a brief background on an issue – for example, a briefing on the inequalities of access to treatments for people with Parkinson’s.

Civil servant: A person in the public sector employed for a government department or agency.

Decision maker: A person who makes decisions in the political arena (for example, a Member of Parliament).

Engagement strategy: A strategy is developed for engaging policymakers’ support. The strategy outlines the obligations, responsibilities, milestones and tasks required to achieve the desired goals and objectives.

ESC: The European Economic and Social Committee is a consultative body made up of representatives of Europe’s

employers’ organisations, trade unions, farmers, consumer groups and professional associations.

ETP: European Technology Platforms are stakeholder groupings led by the industry that help define research and development priorities, timeframes and action plans on a number of strategically important issues.

Eureka: Eureka is a Europe-wide network for industrial research and development.

European Commission Communication: A set of recommendations or facts put forward to the European Council or/and the European Parliament in order to highlight an issue.

European Council Conclusions: A set of priorities that have been voted on by the heads of states of EU members; they must be incorporated into national priorities.

European Council: The European Council defines the general political direction and priorities of the European Union.

The European Commission: The EU’s executive (civil service), it proposes and enforces legislation.

The European Parliament: The body of national representative politicians, it amends and approves legislation jointly with the Council.

European Parliament Resolution: A non-legislative report published by MEPs that focuses on a specific issue.

Executive summary: A term used to describe a brief overview of a longer report or proposal to give readers access to the main information quickly.

Government official: An official who is involved in public administration or government either through election, appointment, selection or employment.

Horizon 2020: The eighth EU programme for funding research. It has a proposed

budget of €80 billion and will address health and environment concerns across Europe.

Joint Research Centre: The European Commission's Joint Research Centre acts as a scientific and technological laboratory in support of EU policies. It has a range of institutes and research activities.

MEPs: MEPs are elected representatives from all the EU member states.

MPs: MPs are national elected representatives.

Messages: Advocacy messages are used to convince and influence people and policymakers to achieve a desired objective.

Monitoring: Following a particular cause/issue/topic, or policymaker/stakeholder.

National competency: The ability to have responsibility and power over particular internal policies and political agenda without foreign consultation.

Non-governmental organisations: A non-governmental organisation (NGO) is any non-profit, voluntary citizens' group that is organised on a local, national or international level. Task-oriented and driven by people with a common interest, NGOs perform a variety of services and humanitarian functions, bring citizen concerns to governments, advocate and monitor policies, and encourage political participation through the provision of information.

Outcome evaluation: The outcome is the concrete result of your engagement activities – such as a change in national policy.

Output evaluation: The output evaluation measures how much you have achieved compared with how much you had planned to accomplish.

Outtake evaluation: The outtake is the impact of your engagement activities on

the policymaker – for example, their perception of your member organisation.

Parliamentary Committee: A group of policymakers that specifically investigates and examines certain issues and reports back to a wider group.

Policy: A plan of action adopted by a person or organisation – for example, a policy on health, transport, finance or foreign relations.

Policymaker: A person who helps to form policy as part of their profession (such as a civil servant). Policymakers can include decision makers.

Position papers: A document that outlines an individual or groups specific position on an issue with recommendations for alternative solutions.

Public health: Public health is the science and art of preventing disease, prolonging life and promoting health through the organised efforts and informed choices of society, organisations, businesses, communities and individuals.

Road map: A detailed plan or explanation to guide you in setting standards or determining a course of action.

Stakeholder: A person, group or organisation that has a vested interest in a particular topic.

Tools: A varied set of instruments used to achieve your objectives. Examples include conferences, surveys, EU policies and position papers.

Tracking: Keeping informed about a certain issue, monitoring engagement and recording outcomes.

Transparency: Transparency means openness, communication and the accountability of an organisation.

White paper: Non-legislative authoritative reports that help guide and educate readers when making decisions.

APPENDIX 6 CASE STUDIES

Here are some examples of European not-for-profit organisations planning and implementing their own successful engagement plans and campaigns.

1. PARKINSON'S UK'S 'GET IT ON TIME' CAMPAIGN

Parkinson's UK (PUK) is a UK-based Parkinson's research and patient organisation. It is the oldest and largest of Europe's Parkinson's organisations and is an EPDA member.

Background

If people with Parkinson's don't get their medication on time, they may lose their ability to manage their symptoms.

Aims of the campaign

PUK launched Get It On Time in 2006 to ensure that the thousands of people with Parkinson's admitted into UK hospitals each year get their medication on time. Specifically, the campaign called for:

- all staff working in hospitals to have a better understanding of Parkinson's and why the timing of drugs is crucial
- hospital staff to listen to people with Parkinson's, their carers and families
- hospital pharmacies to make sure they always stock a broad range of Parkinson's medication
- people with Parkinson's to have the option to control their own medication if they are able to
- people with Parkinson's to get their medication on time.

“
The Get It On Time campaign has encouraged a number of hospitals to review the processes they have in place for PwPs
”

Outcomes

- The campaign has encouraged a number of hospitals to review the medicine management processes they have in place for people with Parkinson's.
- PUK continues to receive positive feedback from patients on improved hospital experiences.
- The campaign won the Ask About Medicines Awards for Excellence 2007 prize for improving communication between healthcare professionals and patients. It was also runner up in the 2008 award ceremony for most innovative approach to medicines information.
- Get It On Time also attracted the attention of MPs and standards groups. In its report, *The best medicine – the management of medicines in acute and specialist trusts*, the Healthcare Commission said: “The opportunity to self-administer should be offered to all suitable patients where timing of their medication is vital, in particular people with Parkinson's.”

www.parkinsons.org.uk/getitontime

2. THE EUROPEAN CHILD SAFETY ALLIANCE'S 'CHILD SAFETY REPORT' CARDS

The European Child Safety Alliance aims to make the lives of children in Europe safer.

Background

Every year more than 10,000 children die in EU countries as a result of unintentional injuries. Hundreds of thousands more are treated in hospitals or emergency departments and risk a lifetime of disability and suffering. However, an estimated 90% of these child injuries could be prevented.

The Child Safety Report Cards are overviews that summarise countries' safety levels provided to their youngest and most vulnerable citizens.

Aims of the campaign

The campaign was devised to allow:

- a comparative assessment of the burden of unintentional child injury
- a comparative assessment of the adoption, implementation and enforcement of national level policy measures that are known to work
- a benchmarking exercise both within countries over time and across countries, which can serve to inspire and motivate further progress
- an important mechanism to identify, share, utilise and adapt the experience gained from across Europe
- an insight into the links between effective policies and health outcomes.

Outcomes

The cards are now used in 32 countries, and the concept has spread to other continents, which means thousands of children enjoy a better quality of life than

they did before. The campaign won a European Health Award in 2011.

www.childsafetyeurope.org/index.html

3. EUROPA DONNA'S 'BREAST HEALTH DAY'

EUROPA DONNA – the European Breast Cancer Coalition – raises awareness of breast cancer across the continent.

Background

About 450,000 new cases of breast cancer are diagnosed in Europe each year and 140,000 deaths occur. Research indicates that as many as one-third of cases could be prevented through changes in lifestyle.

Aims of the campaign

Launched in 2008, Breast Health Day is an annual campaign that reminds women and girls of lifestyle factors that help prevent breast cancer. It uses social networks (such as Facebook, Twitter and YouTube) and other media (a website, videos and print materials) to spread awareness to advocacy groups in Europe.

Outcomes

- Initial results (in 2012) show the digital campaign is reaching its target audience of women aged between 18 and 34. The Twitter campaign showed a reach of more than 150,000 in 2010 and 2011.
- 28 European national groups carried out Breast Health Day campaigns in 2011, up from 22 in 2010. A study has showed that Breast Health Day messages published in media, newspaper, magazines, blogs etc increased by 34% between 2009 and 2010.

www.breasthealthday.org

EB-CLINET'S 'NETWORK OF EB CENTRES AND EB EXPERTS'

EB-CLINET is a clinical network of epidermolysis bullosa (EB) centres and experts; it aims to establish EB centres worldwide to improve medical care for people with EB.

Background

EB is a rare but severe genetic skin disease. Even the slightest touch can cause painful blisters on the entire body: both externally and internally. As EB is a so-called 'rare disease', the quality of specialised medical care is poor in many European countries and needs to be improved.

Aims of the campaign

The EB-CLINET network links clinical expertise in EB and provides a basis to share knowledge, give access to (and improve) medical care for EB patients in all 27 EU member states, and includes as many patients as possible in upcoming clinical studies for potential EB therapies. Other aims include:

- strengthening the collaboration between medical institutions in Europe that already provides medical care for EB
- setting up an online community and database for best-practice care in EB.

Outcomes

- The May 2012 Conference comprised 46 participants from 21 countries.
- There was a very positive response to a scoping questionnaire sent to 39 countries. Replies indicated significant potential for the formal establishment of an EB network and the development of joint initiatives.

www.debra-austria.org

APPENDIX 7 USEFUL LINKS

The EPDA

www.epda.eu.com

EPDA-associated organisations

Find out what other EPDA member organisations are doing with regards to advocacy. It may even be possible to develop relationships and share success stories now or in the future.

www.epda.eu.com/en/about-the-epda/partners-and-supporters/

The European Commission – Health

- <http://ec.europa.eu/health>
- http://ec.europa.eu/health/major_chronic_diseases/policy
- http://ec.europa.eu/health/major_chronic_diseases/diseases/brain_neurological

The European Commission – Research

- <http://cordis.europa.eu/fp7/health>
- <http://ec.europa.eu/eahc/health>

The European Parliament

www.europarl.europa.eu

FINALLY...

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Don't forget that the EPDA has a political affairs and policy team. Do contact them and let them know what you are doing so you can work together to achieve your aims. For more information, email politicalaffairs@epda.eu.com



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