E.S.PKU

THE E.S.PKU ADVOCACY TOOLKIT

Building and Implementing a Successful Engagement Campaign

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THE E.S.PKU ADVOCACY TOOLKIT

Building and Implementing a Successful Engagement Campaign

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> “Together, we can make a difference to the quality of life of all the people with PKU and their families and provide a united political front across Europe”

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Foreword by Eric Lange

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2 2012 WILL BE AN important year for the E.S.PKU and its public policy initiatives to give Phenylketonuria (PKU), the most common rare disease, more priority on European health agendas. As you are certainly aware, the E.S.PKU has launched a European Union (EU) policy programme, and to be most effective and successful, we need the support of our member organisations. Together, we can make a difference to the quality of life of all the people with PKU and their families and provide a united political front across Europe. The E.S.PKU's aim is to build political pressure on Member States by persuading policy makers and guiding healthcare providers in their efforts to comply with the European Council Recommendations on Rare Diseases which outlines a number of strategies to combat rare diseases such as PKU throughout Europe. We hope to advocate for a common goal: More comprehensive and equal PKU services, including diagnosis, treatment and after-care, in current political debates. Building and implementing a successful engagement campaign needs time, the right guidance and a basic understanding of European and national health policies. The E.S.PKU and its members need to be able to influence decision

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> “Together, we can make a difference to the quality of life of all the people with PKU and their families and provide a united political front across Europe”

“Together, we can make a difference to the quality of life of all the people with PKU”

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> makers across Europe and raise our voice in a professional way for people with PKU and their family’s needs i.e. equal access to all treatment options and consistent reimbursement schemes for all patients no matter where they live.

To do this well, we need the right tools and focus our often limited time and resources.

With an educational grant from Merck Serono, the E.S. PKU has therefore produced a practical and ready-to-use advocacy toolkit that will assist you at a national level, to engage with government officials and other stakeholders. The toolkit is a step-by-step guide to planning, preparing and initiating an advocacy campaign.

The E.S. PKU hopes that you will find the information contained within this Advocacy Toolkit useful and will be able to follow its guidance so that each of you can plan, prepare and initiate a strong campaign that can only benefit those, we all have in mind: people with PKU and their families that you all represent at a national level.

Eric Lange,
ESPKU president

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Introduction

THIS TOOLKIT encompasses a simple approach to developing an advocacy campaign, providing guidance on how to initiate policy initiatives to raise awareness of the challenges that many people with Phenylketonuria (PKU) face with the ultimate objective of shaping the national health agenda to better serve PKU patients.

Given the multiple tasks many member organisations (MOs) face for effective advocacy and initiating dialogue with stakeholders at national level, this toolkit has been created as a ‘step-by-step’ guide to planning, preparing and initiating your campaign. The toolkit should be viewed as a ‘live’ document that you can tailor further to your needs and necessities for effective advocacy.

THE OBJECTIVES OF THE TOOLKIT ARE TO:

- Assist you in raising awareness of PKU at a national level
- Help coordinate efforts across Europe thereby reducing the inequalities between countries on issues such as access and availability to all treatment options and care and support for families, which in turn facilitates exchanging best practices between national organisations

TOP TIPS...

Start using the toolkit as soon as possible. If you face any questions please contact us or send an email to info@espku.org as your comments might be also useful to others.

10-STEP APPROACH

The document is divided into 10 steps. For each of the 10 steps, you will find guidance on how to implement them combined with some practical examples.

TAILOR THE INFORMATION

It must be emphasised that the guidance, supporting materials and information provided here need to be tailored to your national situation and complimented with national data and statistics that can help strengthen your outreach to policymakers and third parties.

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> IN USING THE TOOLKIT YOU SHOULD BEAR IN MIND:

- How the guidance and documents provided can be adapted to your national situation
- Complementing the content with additional national or regional information/ data/ statistics
- How you can set achievable goals over a period of time

ADDITIONAL MATERIALS IN ANNEX

Other materials provided to supplement the toolkit include:

- A milestone calendar outlining activities of the E.S.PKU on European level
- A guide to EU public affairs, explaining the different policy bodies and their work
- Template materials that you can adapt to your local needs
- A checklist
- Frequently asked questions
- A list with useful links
- Glossary, explaining key policy terminology

BUILD ON EXISTING RELATIONSHIPS OR START NEW

Although each step is connected and builds on the previous one, the chapters are structured in a way to facilitate quick and easy reference allowing you to access precise information without having to read the entire toolkit. It is just as useful for those who have existing networks as well as those who are beginning their advocacy activities.

WHY SHOULD I USE THE TOOLKIT?

The toolkit can help you to:

- Bring together stakeholders and key advocates
- Create messages which can help you successfully influence national policy and legislation
- Learn about upcoming international milestones in the coming months with key dates
- Inspire your communication through template materials (e.g., letters, press releases, presentations, etc.) to support your advocacy
- Maximise our outreach and impact across Europe.

Building and Implementing an Engagement Plan

1. Understand the Issue
2. Define Your Objectives
3. Know Your Audience
4. Develop your Messages
5. Identify Engagement Channels
6. Choose the Appropriate Tools
7. Build an Engagement Plan
8. Engage
9. Maintain Dialogue
10. Measure Success

EACH OF THE STEPS above is a building block to help you construct a long-term advocacy campaign. A step-by-step approach will allow you to tackle each component separately and adapt the tools provided here so that they mirror the cultural and political nuances of your country. It's always important to remember that all of your fundamental work can be used and reused at a later stage as you develop your outreach.

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Step 1

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Understand the Issue

THE PREREQUISITE TO a successful advocacy campaign is appreciation of the fundamental issues and concerns that people with PKU face and a basic understanding of European and national health policies. This knowledge is the basis of your advocacy campaign.

AT INTERNATIONAL LEVEL (E.S.PKU)

The E.S.PKU's aim is to build political pressure on Member States by persuading policy makers and guiding healthcare providers in their efforts to comply with the European Council Recommendations on Rare Diseases which outlines a number of strategies to combat rare diseases such as PKU throughout Europe. We hope to advocate for a common goal: More comprehensive and equal PKU services, including diagnosis, treatment and after-care, in current political debates.

AT THE NATIONAL LEVEL

Now that you have an overview of activities at the European level, it is time to focus upon gathering information and intelligence available in your country. This might be obvious to you but knowing and understanding the issues affecting people with PKU will help in developing materials, data, and evidence that you can use further in the process when you approach policymakers and third parties.

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TOP TIPS...

Research what's happening at the European level on rare diseases. Visit regularly the E.S.PKU website (www.espku.org) and keep up to date through websites such as the European Commission's Directorate General for Health and Consumers (http://ec.europa.eu/dgs/health_consumer) and Eurodis (http://www.eurordis.org). Good sources for scientific updates are www.pkuworld.org and www.ncbi.nlm.nih.gov/pubmed . As you find information, collate it so that you can refer back to it

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● **Step 1** Understand the Issue

> WHERE TO LOOK?

Here are a few sources of information you can begin with to start collating research, information and data that can help support your case:

- Speak with PKU patients and carers in your country
- Websites of other member organisations on E.S.PKU website (see http://www.espku.org/en/weblinks/37-members.html)
- The E.S. PKU Benchmark report “Closing the Gaps in Care” (available on E.S.PKU website)
- Local/regional and national institutes and universities
- Local/regional and national healthcare providers such as hospitals and health clinics
- Media publications and medical journals
- Professionals and academics specialised in metabolic diseases, dieticians, nutritionists
- Current national policies and plans

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

TOP TIPS...

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 which you can use later in your advocacy campaign and refer back to frequently.

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Define Your Objectives

IT'S IMPORTANT TO clearly define the objectives of your advocacy campaign. These can vary from raising awareness and influencing national health policies, to applying for funding. The objectives can range from being highly detailed (e.g. a targeted lobby campaign to amend legislation under discussion in the parliament) to more generally raising awareness of the challenges PKU face (e.g. the need for consistent diagnosis). Your objectives should be closely tied to those of the E.S.PKU, as national organisations play an instrumental role for an effective Europe-wide lobby campaign.

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E.S.PKU OBJECTIVES

The E.S.PKU`s objectives on EU health policy level is to ensure that PKU as the most common rare disease is prioritised in European health initiatives and appeal that every policy maker has a duty to advocate for optimal PKU care.

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PKU INCLUDED IN EU HEALTH POLICIES

- Ensure that PKU as the most common rare disease is prioritised in EU health initiatives

EQUAL MARKET ACCESS

- Ensure equal access for all patients to the same treatment options across Europe
- Establish lifelong equal reimbursement schemes for all treatment options

IMPROVED DISEASE MANAGEMENT

- Establish standards of care with greater consistency in treatment & after-care across Europe

GREATER PKU VOICE

- Incorporate national organisations into health decision making process

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Step 2 Define Your Objectives

> SETTING YOUR OBJECTIVES

To have a successful national strategy it is important that you keep in mind the European objectives in order to achieving strong synergy across Europe. However, you need to tailor your objectives to your specific needs. Find below some suggestions of broad objectives that you can adapt and think about what tactics you would need in order to achieve them.

RAISE AWARENESS AND ESTABLISH RELATIONSHIPS

- Develop relationships with and provide information to policymakers, insurance bodies, regional associations and the media
- Devlop an alliance of stakeholders (e.g. professionals, industry)

CALL FOR STANDARDS OF PKU CARE

- Leverage results of benchmarkt report through media relations
- Educate care providers, health insurance and social security bodies about optimal PKU care practices

SECURE FUNDING THROUGH NATIONAL/REGIONAL FUNDS

- Organise 3 fundraising events per year
- Investigate if a research institute is interested in benchmarking PKU care against the assessed countries

ENSURE PKU IS INCLUDED IN NATIONAL RARE DISEASE PLAN AND HEALTH POLICIES

- Organise a policy event to educate policymakers

● **Step 2** Define Your Objectives

SET OUT 5 KEY OBJECTIVES WHICH YOU FEEL YOUR ORGANISATION CAN ACHIEVE IN 2012:

KEY OBJECTIVES

1) Raise awareness of the challenges PKU patients and carers face and highlight solutions in the public and policy forums

2) Identify key areas where national policy can be improved and provide input into policymaking

3) Call for harmonized reimbursement schemes of all treatment options including amino acid supplements, low Phe food and drug treatment.

4) ....
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5) ....
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TOP TIPS...

WHEN MAKING THIS LIST REMEMBER TO KEEP IN MIND THE FOLLOWING THINGS:

- How can we link our objectives to the work we already do with media and other stakeholders?
- Can our fundraising efforts help us deliver these goals or can we use our advocacy campaign to help us raise funds?
- How can we ensure flexibility of our objectives so that we can manoeuvre around obstacles?
- How can our objectives be used in coordination with advocacy campaigns that E.S.PKU is organizing on EU level?

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Know Your Audience

ONCE YOU HAVE defined your objectives, whether to raise awareness or to secure funding, you must outline your audience base. Your audience selection can be based upon the below groups; policymakers (health minister and advisors, health authority representatives, healthcare purchasers), media representatives and national stakeholders (academics, medical experts, think tanks, other patient groups etc.).

To understand your audience it is necessary to perform a mapping exercise. The objective of mapping or undertaking an audit of politicians, government officials, media representatives or academics etc., is to identify the main people working of key relevance to PKU. For example, knowing an identified politician's and/or government official's position on relevant issues of concern will enable you to communicate your objective in a more targeted and persuasive manner.

As a starting point for building your audience base, try to gain a clear understanding of the 4 Ps:
- Powers of the national institutions / bodies
- Policy substance
- People inside and outside the policy environment
- Press and media

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Step 3 Know Your Audience

> The questions below can help you determine who to include in your audience base:

THE 4 Ps	CHECKLIST
1 POWERS Power of the institution/ organisation you want to engage with	✓ Who is responsible for healthcare in my country (central vs. regional government)? ✓ Who decides on public spending? ✓ What do we know about the health minister and about his/her political advisors? ✓ Who is the key person behind the decision-making?
2 POLICY The substance that you're trying to influence	✓ What are the national health priorities? ✓ What is the aim of the government's law affecting people with PKU? ✓ How can government projects include our objectives? ✓ What should the law include instead?
3 PEOPLE: Stakeholders outside the Government	✓ Who are the leading academics in this field? ✓ Are there any other patient organisations/third parties with similar messages? ✓ Who are the leading medical experts with an interest in metabolic diseases and in particular PKU? ✓ Who are the industry leaders in PKU?
4 PRESS AND MEDIA	✓ What is the leading medical journal? ✓ Who are the key health journalists? ✓ Has PKU been covered in press and media at all/latterly? What about? >

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> POLITICIANS AND GOVERNMENT OFFICIALS

The starting point for the selection of stakeholders should be the issues of importance to you as an organisation representing the concerns of people with PKU in your country. As the institutional set up and distribution of competencies vary from country to country, it will be important to identify those bodies which are most relevant with regard to a specific issue, e.g. in Germany, certain competencies sit with the regional authorities, the Länder, rather than with the Federal authority.

Relevant decision-makers could include:

- Members of national or regional parliaments that are sitting in the relevant parliamentary committees dealing with health policy or social issues, such as care of the elderly (e.g. Committee on Public Health).
- Government officials in ministries and, more specifically, in ministry departments/units that are responsible for relevant issues (e.g. Ministry for Health and Social Affairs)

The relevance of a politician and government official should be determined in the following ways:

- Power of the decision-maker: identify policymakers who can influence and/or make real decisions
- Keen political interest in the issue
- Political agenda: Research their political parties objectives
- Approachability: Identify policymakers who are active with non-government organisations
- Geographical relevance: ‘all

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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 to you. Being able to position yourself as a voter will make the targeted decision-maker much more approachable and receptive to your messages and concerns.

- Background: Be sure to research your policymaker's background such as their professional and educational history, or even if you find public information on health issues they are interested in due to personal experiences with PKU.

When determining the relevance of a decision-maker, the importance of less senior officials or policy advisors to politicians or ministers should not be underestimated. Within ministries the political guidelines and priorities will be established by the respective minister, but it is in most cases a specific desk officer (civil servant) who will be the expert on an issue and therefore be in a position to considerably influence the overall position of the ministry on that particular issue. 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

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influenced and shaped by their respective policy advisors.

The more information you have about your target, the easier and more efficient your task will be. You can find out a large amount of information through the following ways:

- Look at the organogram of the body in question to see who is heading or sitting within the units/departments that are dealing with a specific topic (e.g. Ministry, membership of specific parliamentary committees)
- Do an internet search of his/her name
- Examine a decision-maker's public communication, e.g. speeches, press releases, memoranda or other documents, participation in relevant events, own websites (e.g. especially relevant for politicians)
- Examine their political party and the party's health and funding objectives
- Ask a friend, colleague or a medical expert. Use your connections
- Use your local government branches to gather information on national politicians
- Gather intelligence through trusted third parties/experts

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TOP TIPS...

Researching your targets may take time but be sure to keep all information you come across. You will also come across policymakers that may not be high in your priority list but can become relevant at a later stage. Maybe hire a student or ask for volunteers within your organisation supporting you in the mapping exercise.

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> EVALUATION OF A DECISION-MAKER'S POSITION AND INFLUENCE

For each decision-maker identified, a thorough assessment of his/her likely position towards your organisation and the respective key issues as well as his/her ability to influence relevant audiences should be carried out. This can seem like a discouraging process but a wealth of information can be found on the internet and this is a good place to start the research process. Many political figures will have their own dedicated websites that can tell you about their own interests and campaigns they have championed. By undertaking this research, you can start to build a picture about the individual.

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These are the research criteria:

a) Position

Based upon the information found when researching a politician and government official's issue-related activities (e.g. speeches, press releases, questions asked in parliament, motions raised, etc.), the position or attitude of a politician and/or government official towards an organisation representing the concerns of people with PKU and the respective key issues should be assessed. In the case of policymakers, the analysis of their positions on specific issues should not only be based upon their own activities and comments but also on activities undertaken in the name of the Ministry or policy institution they work for, e.g. their political party (party electoral programmes, speeches at party conferences).

Politicians' and government officials' overall attitude

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towards your organisation and/or on specific issues should be rated on a scale of 1 – 5 with the ratings having the following meaning:

1 = very critical
2 = critical
3 = neutral
4 = positive
5 = very positive

A neutral rating should be given in the following cases:

a) Where a politician and government official does not have a negative or positive opinion on the issue
b) Where they have a balanced position. This could be, for instance, also in cases where they are moderately critical with regard to a single but not fundamental aspect of an issue and do not challenge the underlying policy principles
c) Whenever it proves impossible to evaluate a position due to the lack of publicly available information

b) Influence

After the assessment of the attitude of politicians and government officials, their ability to influence the general public's opinion, specific relevant authorities (e.g. payers) and/or other politicians and government officials and the health community should be assessed. In doing so, the focus should be on their ability to influence these audiences in general terms as well as with regard to the specific issue(s) for which he/she was identified as relevant.

The evaluation of a politician's and government official's influence can be challenging because information about

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> 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 his/her organisation (government department or political party) and evidence of past instances in which the politician and government official 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 cited in the press, as this indicates that what he/she says is considered to be influential. The influence should also be rated on a scale of 1 – 5 with the ratings having the following meaning:

1 = no influence
2 = low influence
3 = influential
4 = very influential
5 = highly influential

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> The outcome of the assessment of position/attitude and influence will provide the basis for a set of initial recommendations on priority, willingness to engage, means of engagement and messages for each politician and government official. Here is an example of identifying a policymaker at the national level:

NAME AND CONTACT DETAILS	RELEVANCE	ATTITUDE TOWARD SPKU	POSITIONING AND INFLUENCE	ENGAGEMENT RECOMMENDATION
Dr. Ann Mackie	Director of Programmes UK National Screening Committee Imerial College Healthcare NHS Trust Dr Mackie is in charge of overseeing and implementing screening for rare diseases in UK.	Valuation: 4 (Positive)	Evaluation: 4 (Very influential) - General public/media” 2/3 (low influence/influential) - Policmakers/Government officials:4 (Very influential) - Healthcare community: 4 (Very influential) - Patients: 4 (Very influential)	NSPKU should establish outreach to Dr. Mackie and continue to liase with her closely on the issue of national implementation plans and providing input which will then feed into the European level.

The stakeholder matrix should provide a visual description of the prioritisation of the politician and government official identified on the basis of their attitude and influence ratings and will help you to strategically select your priority targets for engagement.

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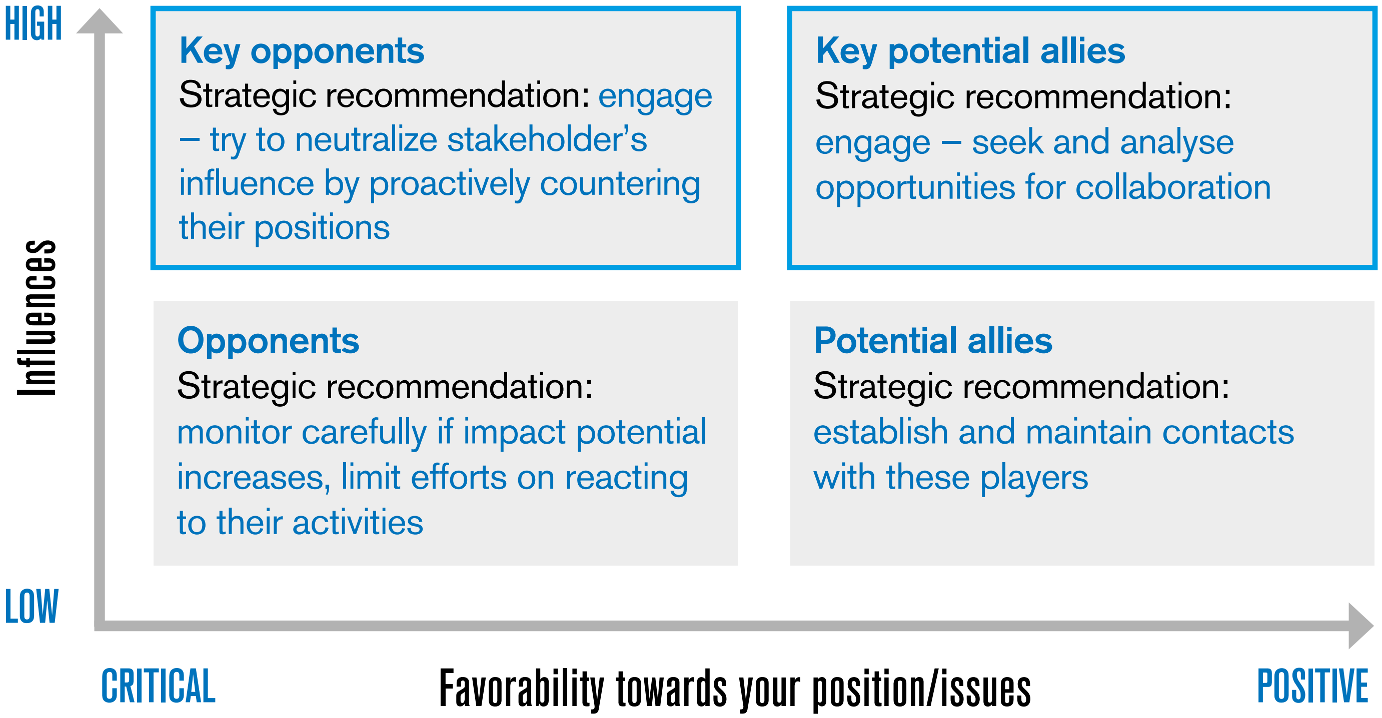

Key opponents
Strategic recommendation: engage – try to neutralize stakeholder’s influence by proactively countering their positions

Key potential allies
Strategic recommendation: engage – seek and analyse opportunities for collaboration

Opponents
Strategic recommendation: monitor carefully if impact potential increases, limit efforts on reacting to their activities

Potential allies
Strategic recommendation: establish and maintain contacts with these players

> DEVELOP PRIORITY MATRIX

This is an activity which can help chart which policymakers and stakeholders can be key allies as well as identifying actors which may be challenging. Each politician and government official can be framed into a 2x2 matrix with the horizontal axis indicating favourability towards the relevant issue and the vertical axis indicating influence. The matrix should be divided into four squares. Depending in which square a decision-maker is located, he/she would fall into one of the following categories:

- Key potential allies/advocates (positive and influential)
- Potential allies/advocates (positive but low or no influence)
- Key opponents (critical and influential)
- Opponents (critical and low or no influence)

For each of these four categories the following initial strategic recommendations can be made (see table above).

The individuals situated in the top two squares (key opponents and political allies) should be the primary targets for engagement.

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> Other criteria to consider:

- Approachability: start your engagement with those who are more approachable, e.g. who is open for a dialogue with your organisation?
- Geographical relevance: the constituency element is often important especially when engaging with politicians. For the first round of engagement, you could prioritise those in whose constituency you have a presence (e.g. where 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 approachable and receptive to your messages and concerns.

THIRD PARTIES

To have a successful national campaign it is imperative that you focus upon extending your audience base beyond policymakers and government officials. Third parties can involve doctors, academics, dieticians, industry, university professors, influential individuals (e.g. blogger) and other patient organisations. These groups cannot make national decisions but are greatly influential in building a strong campaign and in influencing policymakers. Policymakers and government officials take great heed of academics and medical experts. More and more we see these non-government people speaking at political conferences, attending public hearings and adding to national debates. Unlike policymakers, academics and medical experts are more accessible for national organisations to meet and often have more empathy for your cause.

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TOP TIPS...

HOW TO FIND YOUR KEY THIRD PARTY:

- Search key people who have been involved with Phenylketonuria or Allied Disorders in your country
- Examine the project leaders in university research projects
- Read national health publications and medical journals
- Research other successful patient organisations
- Attend university debates, medical seminars and public hearings to get an understanding of which the key people are that would be an advantage to your organisation. Informal meetings are a great way to make connections and to profile your organisation.

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MEDIA

The media holds a powerful influence over national governments; it has the ability to influence the electorate, reports on government affairs and is interested in political decisions and policy objectives. In order to catch the interest of both the policymaker and the media, it is necessary to build a relationship with your national or regional media.

National newspapers and specialised healthcare media are all key targets for media outreach. These publications reach not only People with PKU, but also carers, innovative leaders, and healthcare professionals. Where resources are available, you can use a media database such as MediaAtlas or Gorkana to identify appropriate media outlets and contacts. If you work with a public relations agency, they can help you do this. Alternatively, you can use online search engines such as Google to manually identify national/regional media contact information. The media will be a vital tool when raising the profile of your organisation and for achieving the attention of policymakers, government officials and other third parties. ■

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Developing your Messages

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KEY MESSAGES FOR POLITICAL STAKEHOLDERS

IT IS IMPORTANT FOR THE engagement strategy to have the right messages in place. Often politicians and policymakers have heard the problems numerous number of times, therefore it is your aim to provide them with solutions. Building upon your growing network with third parties (medical experts, academics, industry) you can construct messages which will grab the attention of policymakers and influence them to change.

PRINCIPLES FOR DEVELOPING KEY MESSAGES

In order to succeed in any engagement strategy, it is important to get the right messages to the right audience at the right time. Therefore the messages have to be carefully crafted and speak to your key objectives. Note that every target audience has its own wants and needs.

Therefore messages needed to be adapted according to which audience group they are targeted at:

1. **Patient groups**: public awareness, patient outcomes, funding
2. **Clinicians**: outcomes, funding, autonomy, empowerment
3. **Opposition**: headlines, scrutiny, policy changes
4. **MPs**: constituency, personal interests, fairness, career progression
5. **Civil servants**: problem solving, efficiency, reducing workload, data/information
6. **Ministers**: political narrative, national constituency, party considerations
7. **Media**: headlines, patients/ public, social aspects

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● **Step 4** Developing your Messages

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> It is important that where possible your key messages are backed-up by facts, figures, specific programmes, initiatives, personal/emotional impact or collaborative efforts. Therefore, take the research, policy and political context into account and, wherever relevant, ensure a:

- Local & regional angle
- European and/or global perspective
- Be reinforced by concrete facts and figures
- Emotional angle, e.g. patient story

Once the messages have been shaped, they form the basis for on-going dialogue with your key targets and will be vital to extend your on-going communications and media strategy around your national campaign. >

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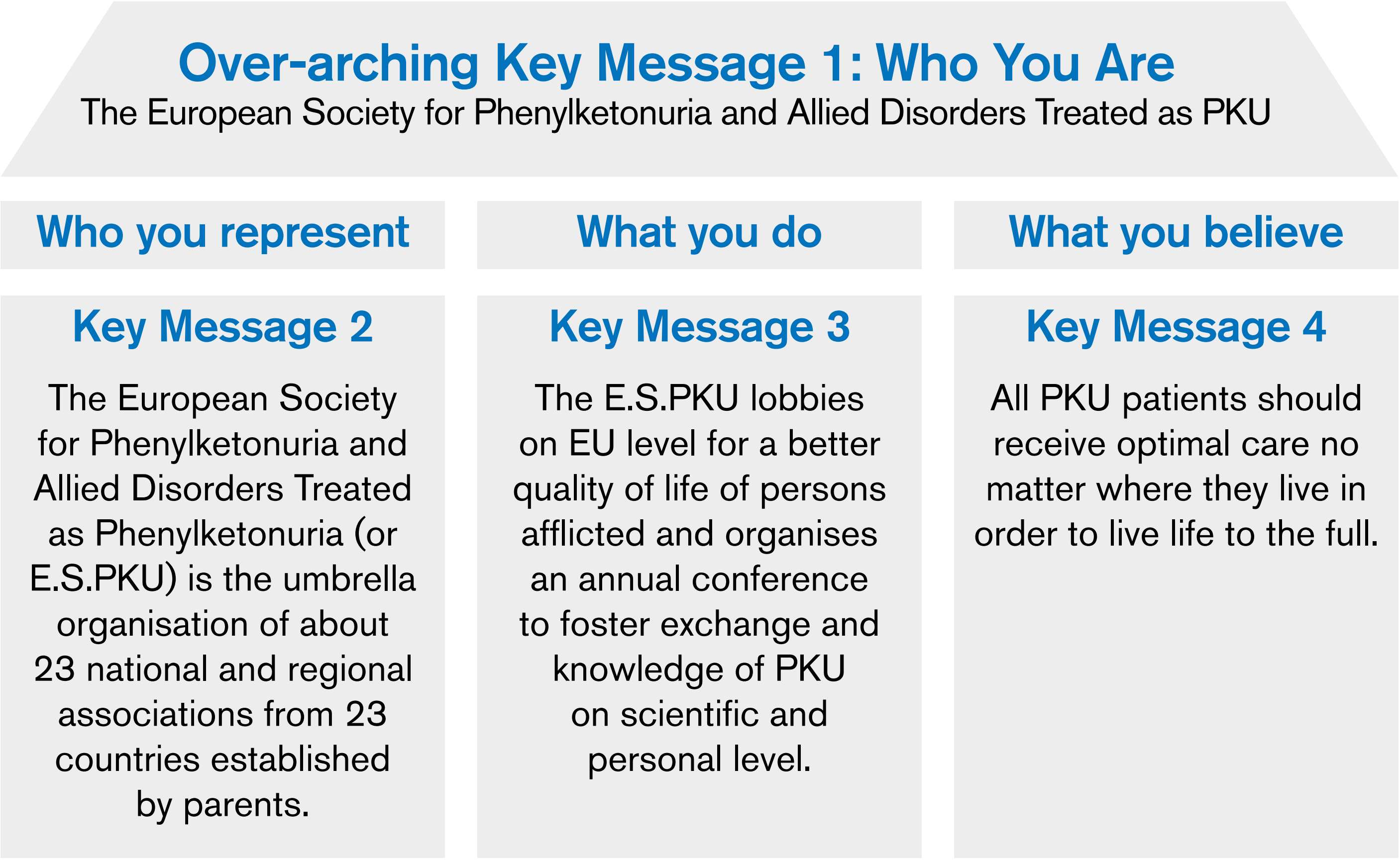
> GUIDANCE ON DRAFTING YOUR MESSAGE

Communicators often use the so called “message house” methodology to develop messages. The message house is the architecture within which the messages sit. In short, it has one over-arching position statement or “mission”, followed by supporting key messages that make-up the three pillars. You can travel from one pillar to another to help you build the flow of a story. 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.

Below is an example of the corporate message house of the E.S.PKU. However, you may develop a message house on a particular issue that you wish to communicate on, in which case the messages are more likely to vary for your different stakeholders. ■



Over-arching Key Message 1: Who You Are

The European Society for Phenylketonuria and Allied Disorders Treated as PKU

Who you represent	What you do	What you believe
Key Message 2	**Key Message 3**	**Key Message 4**
The European Society for Phenylketonuria and Allied Disorders Treated as Phenylketonuria (or E.S.PKU) is the umbrella organisation of about 23 national and regional associations from 23 countries established by parents.	The E.S.PKU lobbies on EU level for a better quality of life of persons afflicted and organises an annual conference to foster exchange and knowledge of PKU on scientific and personal level.	All PKU patients should receive optimal care no matter where they live in order to live life to the full.

Identifying Engagement Channels

ONCE YOU HAVE completed your research, defined your objectives, identified your key audience and developed your messages, you must decide on your engagement channel. How to best meet with your audience and interact? We recommend having a twinned approach; both direct and indirect engagement.

DIRECT ENGAGEMENT STRATEGY

- One-to-one meetings with your priority policymakers, third parties and media representatives: these are the most common and effective engagement tool.
- Events

INDIRECT ENGAGEMENT STRATEGY

At times, it can be difficult to organise meetings especially with policymakers and politicians. Do not be discouraged as there are other opportunities for indirect engagement.

- Participate at speaking platforms (secure speaker placement at leading events)
- Form alliances with other patient associations
- Publishing Reports
- Send out letters/briefings/ press releases to your target audience
- Make submissions to national projects
- Attend medical workshops/ university debates

TOP TIPS...

Find a sparring partner within your organization or ask a friend to use him/ her to exchanging ideas, running role plays as rehearsals to test your engagement approach.

KEY PERSONALITY SKILLS FOR ENGAGING SUCCESSFULLY:

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

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Choose the Appropriate Tools

THE TOOLS IDENTIFIED and outlined below provide examples of successful means for engagement with a target audience. Here are examples of the different types of tools you can use as part of your advocacy campaign:

EVENTS

Organising or sponsoring an event, workshop, and/or debate could take many different forms with different degrees of engagement. The event has to be carefully planned and prepared, including questions & answers considered in advance. When thinking of organising an event, first consider the following points:

- What is the issue/ topic you would like the event to focus on?
- Is the event part of a larger strategy that will help meet your overall objectives?
- What can be the best timing for you to organise the event and are there any events in the political arena, such as publication of a national policy that you could coincide your event with to maximise exposure?
- Who would be your target audience?
- What are your key messages?
- Who should be involved (speakers, third party, etc)
- What is your ideal outcome?
- How would you follow-up after the event?

1) Content events

An example of this kind of event is a conference, seminar or workshop organised by your organization where you invite an academic, politicians and/ or government officials to speak or participate in a discussion on a particular issue/ topic. While increasing the value and weight of the respective event, you would at the same time be providing the members of the target

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> group with a platform to profile themselves.

2) Event co-hosted with another organisation

There may be the opportunity to co-organise events with other organisations such as a reputed university, research institute or think tank, where there is a common interest or where the organisation in question has collaborated with you on a piece of research or a report. The engagement of another organisation would lend further credibility to the initiative and create an opportunity to invite a politician to speak at the event.

3) Parliamentary events

Organising a parliamentary event would allow you to reach out to more than one Member of the Parliament at a time. The fact that any event organised in the premises of the national Parliament needs to be officially hosted by a Member of the Parliament provides a special relationship building opportunity.

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Although the Member of the Parliament is generally doing the organisers a favor by accepting to host the event, it at the same time provides him/her with a profiling platform via-a-vis his/her colleagues, especially if the event is organised around a topic of political interest to him/her.

Depending on the national political culture, two different event formats are usually possible: a cocktail reception which allows for numerous but passing interaction with contacts or a lunch/dinner debate which provide the opportunity for a higher quality of engagement with a smaller number. At lunch/dinner debates, parliamentarians will >

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be seated around tables with representatives and actively engaged in a discussion for about 2 hours.

4) Site visits

These can be highly effective relationship building platforms, giving 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, e.g. inviting Member of the Parliament and/or government officials with a specific policy interest (e.g. health policy, rare diseases, endocrinology diseases) or a geographical dimension, e.g. inviting your local Member of the Parliament to visit and meet people with PKU to discuss their perspectives and issues that affect them.

The attractiveness of a site visit could also be increased by inviting local colleagues of the Member of the Parliament, e.g. members of regional or municipal assemblies of the same party, or local press as it would provide the MP to profile himself vis-à-vis his home constituents. A site visit can also be coordinated with any fundraising work you are doing as well as being an opportunity to highlight your organisation in the media.

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● **Step 6** Choose the Appropriate Tools

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> PERSONAL MEETINGS

Personal meetings form part of the direct engagement channel with your audience (see Step 5), this is one of the most effective tools for getting your messages across. It is also an essential part of the process of building long-term relationships. Examples of success in this case would be where your views or input is then proactively asked for by the politicians in question. This could range from being approached to feed into draft legislation and policy, or being invited to participate and speak at expert hearings and workshops.

In order to make your personal meeting successful you need to consider the following:

- Target the people that matter. Your political stakeholder mapping (see Step 3 above) should identify a core group of about 15 - 30 contacts in your market (depending on the political structure and its scope).
- Respect the level of decision-making. Legislation is drafted by experts and officials at the lower level, and your starting point will be to contact those. Approaching higher political levels will be more beneficial in the case of lack of interest in addressing your issues, negotiation deadlocks, or high political stakes.
- Ensure your representative is comparable to your interlocutor in terms of seniority and influence (e.g. a Minister should be met by the head of your organisation).
- Do your homework on the interlocutor. Know what she/he wants and might expect from a meeting.
- Ensure that you meet

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expectations. Give information, suggest policy change and offer networking advantages.

- Arrange the meeting at the right time in the policy and/or regulatory procedure.
- Sustain contact when you do not need help.
- Offer technical assistance even when no critical issue is at stake.
- Always leave something behind (executive summary / position paper or ‘gimmick’) to remind them of your visit and advance your key messages.
- Follow-up with a thank you letter and send through any additional information that may have been requested.

Remember that the earlier you intervene in the policy process, the more successful the end result is likely to be. Building relationships before the issue becomes urgent is important. This will mean that you aren’t just turning to the official in times of crises and 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 better 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 a tight agenda. A meeting for a meeting’s sake is therefore not advisable. Personal meetings should be reserved for times when an issue is being focused on, even if very early in the process.

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TOP TIPS... BELOW ARE KEY TIPS FOR ORGANIZING A ONE-TO-ONE MEETING:

1) Form a Strategy

Send an introductory email to your target. Follow up 4-5 days after the email with the assistant. Be respectful and polite to the assistant 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 be transparent about your objectives. Honesty and openness will be respected and enhance your reputation.

3) Know what you want to achieve and be flexible

Be clear on what your objectives are and provide solutions not problems. Be realistic and practical. Always be prepared to adapt your strategy to new developments.

4) Be prepared

Try to familiarise yourself with a politician's opinion before you communicate with him/her. 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 will likely put him/her in a defensive position, undermining the potential for a 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/points and focus on the most relevant ones). Remember to use your research and independent evidence.

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> Expand on your knowledge of EU polices and the work done at the EU level.

6) Add value

Politicians are in the business of winning votes. If you can make a politician look good to his/her voters this will help you build a positive working relationship. Politicians like media – so provide them with media profiling opportunities.

7) Never underestimate the importance of policy advisors and assistants

Policy advisors are not only gatekeepers but also shape their politician's opinions. They are often more accessible than politicians. Thus, if you cannot meet the Minister, do not hesitate to meet the advisor. Be sure to be polite as future relationships rely on a good working environment.

8) Be confident

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

9) Follow up

Send a follow up thank you email.

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> LETTERS / EMAILS

Letters are normally either linked to a follow up process from an earlier meeting, speaking opportunity or drafted in connection with a position paper. Follow-up is vital to the success of your engagement. Every meeting you have and initiative(s) you organise needs to be followed up with a letter/email or phone call. Writing a thank you letter to a government official you have met will give you an opportunity to restate your arguments (or key messages) and reiterate your expectations, and finally to offer your cooperation with his/her future activities.

The key objectives and recommendations for drafting letters are:

- To support a position paper, a short cover letter is almost always useful
- 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
    - Increase the chances that you will receive a positive response
- Personalised letters should always be used when targeting high-level politicians, officials, or other decision-makers
- Thank you letters

But meetings will often be the only way to ensure a point gets home!

Dear Mrs/Mr …

On behalf of XXX, again many thanks for hosting last Wednesday's Parliament reception, which marked the official launch of the Benchmark Report "Closing the Gaps in Care". 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 report itself and the launch event have of course been our main priority for quite a while, and it was highly rewarding to see such a broad group of participants supporting the initiative through their presentations as well as the great interest in the call-for-actions. Perhaps even more impressive, it was inspiring to note the consensus on some of the actions that need to be taken to ensure equal access to all treatment options for PKU and a standardised approach in reimbursement. We appreciate the commitment of the many participants – including your own – to support and effectuate change.

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

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> Position papers

Providing policymakers and third parties with position papers and targeted briefings allows you to further explain your position and include key facts and case studies. This is an important tool as it allows you to state your organisations position regarding a certain policy/issue that affects people with PKU and the document sends out your message in print thereby strengthening your advocacy campaign. It can be used as ‘leave behind’ in a meeting or shared with your audience at an event you organise.

You should bear the following in mind when constructing a position paper:

- Keep it short (one page is ideal), concise and consisting of your messages
- Tailor your paper to your audience – think what is important for them and go with the grain of their politics/ administrative culture
- Focus on the top two / three concerns (Tip: You can use identified areas from your research or from the Benchmark Report)
- Be as concise as possible and get to the point quickly – politicians and government officials in particular have limited time and no obligation to hear your views
- Always try to provide an executive summary of the position paper if it is longer than two slides
- Support arguments with relevant factual details – but provide technical information and references in annexes, not in the body of the text
- Be positive and constructive – try to avoid using an aggressive tone
- Always suggest solutions as well as highlighting problems (e.g. propose recommendations)
- Recall that ‘the devil is in the detail’. Highlighting unknown consequences could add to your position as a trusted source of reliable information and advice

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> MEDIA OUTREACH

The media can be an accessible channel if you have the right content. There are several ways to engage with journalists, radio and television:

1) Get to know your contacts

It is always a good idea to know what your target outlets and specifically, target reporters usually write about before reaching out to them. This extra research will help ensure that you have identified the appropriate reporter to pitch with this type of story. Reporters in particular appreciate it when you can reference a past article they wrote.

2) Develop your media objectives

Develop a story which the media would be interested in. A good tip would be to use your knowledge of EU activities and how they can be compared/ contrasted to the national situation. The story can be either distributed through a press release (if there is a news angle to your story) or as a background/feature story

3) Don’t give up

Often journalists are interested in covering ‘cutting-edge’ stories; tell them that your organisation is changing national health priorities. Like in all engagement rules, follow-up calls are a necessity.

You should bear the following in mind when drafting a feature:

- Structure: The introduction is the most important part - entice your reader, hook them in. Use drama, emotion, quotations, questions, descriptions. The body of the article needs to keep any promises or answer any questions raised in the introduction. The conclusion should be written to help the reader remember the story -

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Step 6 Choose the Appropriate Tools

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> use a strong punchline.

- Focus on human interest - the feel and emotion you put into the article are critical.
- Be clear about why you are writing the article. Is it to inform, persuade, observe, evaluate, or evoke emotion? Write in the active voice. In active writing, people do things.
- Accuracy is important - you can interpret and embroider but not fudge.
- Avoid clichés (cutting edge, world beating, revolutionary) and sentimental statements, especially at the end of your article.
- Use anecdotes and direct quotes to tell the story - try not to use too many of your own words.
- READ the publication you want to write for (a surprising number of writers don't and it shows) ■

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Step 7

Build an Engagement Plan

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COMMITMENT AND CONTINUITY

AN ENGAGEMENT PLAN has to be considered in the context of building relationships over the long term. In simple terms, you can imagine the engagement process as follows:

The engagement plan has to factor in the following overall objectives:

- Adding value: understand needs
- Building trust: be honest and transparent
- Invest consistently: maintain regular contact
- Be considerate: do not overstretch the relationship
- Be patient: long-term vision

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Step 7 Build an Engagement Plan

Fatma

> TEAM/RESOURCES

In the planning stages of your engagement strategy, you also need to consider who will be involved from your organisation and under what responsibilities (structures). Whether your team is large or small, ensure you have allocated responsibilities for each member. 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 so your organisation engages with policymakers in a more manageable manner. Whilst organising your team's workload, bear in mind:

- Who needs to be involved?
- Who will coordinate the campaign/activities?
- Who is responsible for each channel?
- Who is responsible for which issue/topic?
- Who is the key contact for each policymaker/ stakeholder?

The engagement plan can be divided into different work phases that are structured around the political process. Below you will find an example of how the implementation of your engagement plan can be structured. Of course, you need to consider your national political system and adapt it accordingly.

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Step 7 Build an Engagement Plan

Fatma

> The process described on the right shows that there can be many opportunities whereby stakeholders, such as your organisation, can lobby parliamentarians indirectly or directly, in order to influence proposed legislation:

- 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
- During initial discussions, create opportunities to have targeted meetings with parliamentarians on relevant committees and propose amendments via parliamentarians that are supportive to people with PKU in your country
- If there is a conciliation phase, monitor how your messages/ amendments are discussed in parliament and continue lobbying of parliamentarians to ensure that any of your key concerns which have not been addressed are highlighted
- Finally, monitor the vote. If the vote does not go your way, then continue to engage and sustain dialogue with those who have supported you to look at other opportunities to further your cause. ■

CASE STUDY: THE FRENCH POLITICAL SYSTEM

France has a bicameral system so you need to engage with both the National Assembly (Lower House of Parliament) and the Senate (Upper House), which will examine the proposal. The legislative procedure in France starts with both houses reading the proposed legislation, examining the text and exchanging their amendments to the proposal. If they cannot come to an agreement on the changes to the text then a 'conciliation' committee is convened composed of members both from the National Assembly and the Senate. The next stage involves further discussions and making compromises in order to come to an agreement on the text. If at the latter stage there is no agreement, then the text is voted upon by the National Assembly solely and it decides on whether or not the proposal with its amendments will be accepted.

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Engage

PRIOR TO ANY PLANNED meetings, preparation is the key. You will only be successful in achieving your goals if you have done your homework according to the steps we have outlined previously. This is particularly the case for government officials/politicians.

DO YOUR HOMEWORK

You need to be prepared and expect to address the following:

- Background briefings of the official/politician you're engaging with (see example in annex)
- Know his/her interests and position on the issue at hand
- Show knowledge of the political and policy process
- Be able to show that you know of other political groups/ departments positions
- What is your key message (top three/four messages from your message house)
- Be able to highlight how the issue/ topic impacts people with PKU (give concrete examples)
- Wherever possible exemplify with local/regional perspectives (link to the parliamentarian's constituency)
- What are your recommendations for actions?
- What would you want the politician/government official to do for you?
- How can you help?
- Offer to follow up with case

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studies and research that will assist the politician/official in his work

- Provide targeted leave behinds, such as position paper, fact sheet or case studies

DURING ENGAGEMENT

In short, when engaging with politicians/officials you need to consider the following:

- Be Relevant: Understand context & timing
- Be Knowledgeable: Know your case and audience
- Be Constructive: Offer solutions, options, intelligence, support
- Be Respectful: Build bridges, develop trust, value partnerships

And last, but not least, given the importance of policy advisors in shaping their superior's opinions, do not hesitate to meet the advisor if you cannot meet the boss. ■

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Maintaining Dialogue

Maintaining the dialogue following your engagement is crucial to positioning your association as a trusted and reliable partner. Immediate follow up from a meeting with up-to-date research, case studies, data etc. sets the tone for your future contacts. It is not only about seeking to win short-term goals but about creating an atmosphere of trust and confidence. It is important also to remember to sustain the dialogue even when there is no issue at stake.

PROACTIVE ENGAGEMENT AT THIS STAGE INCLUDES:

- Follow up from meetings, events, with studies, research, fact sheets, including thank you letters/email/phone call
- Provide your contact with new studies, research and case studies as soon as these are available
- Invite your contact to conferences and hold private briefings
- Share information that you know is of interest to them
- Proactively inform and share information on viewpoints from other stakeholders
- Offer your expertise and network

With a view towards a continued successful engagement, you need to consider:

- Multiple processes: Cover different actors on different process levels
- Changing priorities: Anticipate and adjust
- Changing phases: Match messages to realities
- Multiple organisations: Create networks / extend alliances

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Step 9 Maintaining Dialogue

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> Tracking engagement activities Maintaining the relationship with your political stakeholder is as important as initiating the relationship in the first instance. This can be 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 that you can share your results with other organisations but also for your own benefit to see the progress you have made in building a network of political support and to follow-up on next steps. An example of an engagement tracker can be found below: >

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CONTACT DATABASE

For bigger organisations, where several people could potentially be involved in engagement and communication activities with decision-makers, it is recommended that a comprehensive contact database is created. The purpose of the database would be to avoid duplication of efforts and counterproductive communication or engagement activities. It is the main coordination tool providing a central work space containing the details of all decision-maker contacts as well as status reports on past activities. The database should allow each member of the organization to actively update the status reports after each activity, e.g. meeting with a journalist, policymaker etc. A good value for money solution is to create an xls sheet containing the following information on each decision-maker:

- Contact details
- Background briefs (professional/political bio, issue interest, general attitudes)
- Contact owner within your organisation
- Relationship history (overview of past meetings incl. comments and outcome)
- Activity planner (outstanding actions, planned meetings, etc.)

The relationship history and activity planner elements in particular will turn the contact database into an effective campaign management tool which will help coordinate your engagement activities. ■

TOP TIPS...

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

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Measure Success

> “Ugias nam haru mquidere non peribus quibust ma verate voluptia nossinv eruptum aliquia ssecull”

EVALUATING THE EFFECT that your activities have is extremely important in measuring their impact and in planning future activities so you improve on your outcomes.

EVALUATING A ONE-TO-ONE MEETING

When setting up and attending a meeting with a political target you should always have an agenda in mind and an expected outcome. After a meeting, consider whether you achieved the outcome you required. If not, are there follow-up actions you can undertake to achieve your goal or you may 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 exit questionnaires to gauge what your audience thought of your 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 recommendations for improving the event?

EVALUATING THE PROGRAMME

Consider overall 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 engaged with, the impact of your engagement on decision-maker attitudes/perceptions of your organisations and the impact of your activities at a political level in terms of raising awareness of a particular issue or garnering support. Keep your engagement tracker up-to-date to help you when you come to evaluating your programme.

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> There are three possible levels of measurement:

1) Output evaluation
– what has been delivered
As the most basic form of evaluation, this is concerned with what activities have been undertaken against the goals and timelines established in the engagement plan.

2) Outtake evaluation
– impact on decision-makers' attitudes/perceptions
This is the impact your engagement activities have had on the targeted stakeholders.

3) Outcome evaluation
– impact on your organisation

The outcome in terms of concrete results of your engagement activities are by far the hardest element to measure, particularly if your engagement is not specifically linked to changing a piece of legislation. It may take longer periods of time (often years) before a situation changes and the impact of engagement activities becomes measurable for your organisation. >

Step 10 Measure Success

	WHAT MIGHT BE MEASURED	MEASURING TOOLS
OUTPUT	✓ Did we do what we set out in the engagement plan? ✓ How many decision-makers have we engaged with directly or indirectly?	✓ Number of stakeholders engaged with ✓ Number of people attending a conference ✓ The media coverage after an event.
OUTTAKE	✓ What messages did the targeted decision-makers take away from our engagement activities? Were these accurate and positive? ✓ How far did our engagement activities affect the perception and attitude of the targeted decision-makers? ✓ Did decision-makers act in line with our objectives (e.g. introduced amendments to draft legislation)?	✓ Monitoring and analysing decisions taken (e.g. 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) ✓ Statements (e.g. press releases, position papers, speeches) made by your target stakeholders for possible changes in attitude and the position it is taking vis-à-vis PKU.
OUTCOME	✓ What is the end result of our activities? ✓ Did we achieve our goals? ✓ How did we change behaviour? ✓ Did we create a stronger preference for our cause and for PKU?	✓ Change in national policy/ legislation ✓ More support via national government policies for PKU ✓ An overall increase measured over a long period in time (1-5 years) in awareness of PKU

The E.S.PKU Activity Calendar

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A Guide to EU Public Affairs

Fatma

PUBLIC AFFAIRS

PUBLIC AFFAIRS IS A broad topic that can be defined as a process aimed at influencing public policy, building and maintaining strong relationships and raising awareness in order to achieve a certain aim. Two core tools in public affairs are knowledge and communication; knowledge of the decision-making process, key policymakers and public policy whilst having the ability to communicate messages to a wide audience. Therefore, public affairs is central to influencing decisions in the European Union. One of the main activities in public affairs is advocacy.

ADVOCACY

Advocacy is a catch-all word for a set of skills used to influence public opinion and make policymakers and politicians more aware of public needs. Advocacy is a practice more than a concept, in other words it means: specific actions are taken to achieve specific aims and goals. Advocacy is used to strengthen the voices of a wide range of groups at the local, national and European level. In order to reach this point, patient organisations, industry, NGOs and a variety of other actors embark on an advocacy campaign. The key to a successful advocacy campaign is to gather widespread community and national support; this can be achieved through building coalitions, collaborating with national organisations, encouraging community activity, fundraising and connecting with the media. The best kinds of campaigns should build a strong sense of community, raise awareness, build alliances and work towards shaping both national and European views. For an effective national campaign, knowledge of the European Union is vital.

WHAT IS THE EUROPEAN UNION?

To implement a successful national advocacy campaign it is useful to have a good knowledge of the European Union (EU),

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basic health policies and priorities.

The EU is a unification of 27 states aimed to create a political and economic community throughout Europe. Though the idea of the EU might sound simple at the outset, it is a complex web of cultures, traditions, and systems. The European ultimately brings together 27 member states under a common system of law, established by a series of treaties.

The EU is predominantly governed by three Institutions: the European Council, the European Parliament, and the European Commission.

The Council of the European Union is the main decision making body in the EU. It is presided over by a Council President. Each Member State takes a six month term in the position. The Council has legislative power and makes decisions through a voting system made up of Member State representatives.

The European Parliament is an elected body representing the needs of EU citizens. Currently there are 736 Members of the European Parliament representing the 27 Member States. These representatives are the most accessible policymakers for national organisations.

Finally, the European Commission is the executive committee, which manages the EU with the aid of Commissioner's from each Member State. Its main job is to uphold the common interest of the EU.

HEALTH IN THE EUROPEAN UNION?

Health is a national competency in the EU. This means that each EU country is free to decide on the health policies best suited to national circumstances. These include the right of everyone to the same high standards of public health and equity in access to quality health care.

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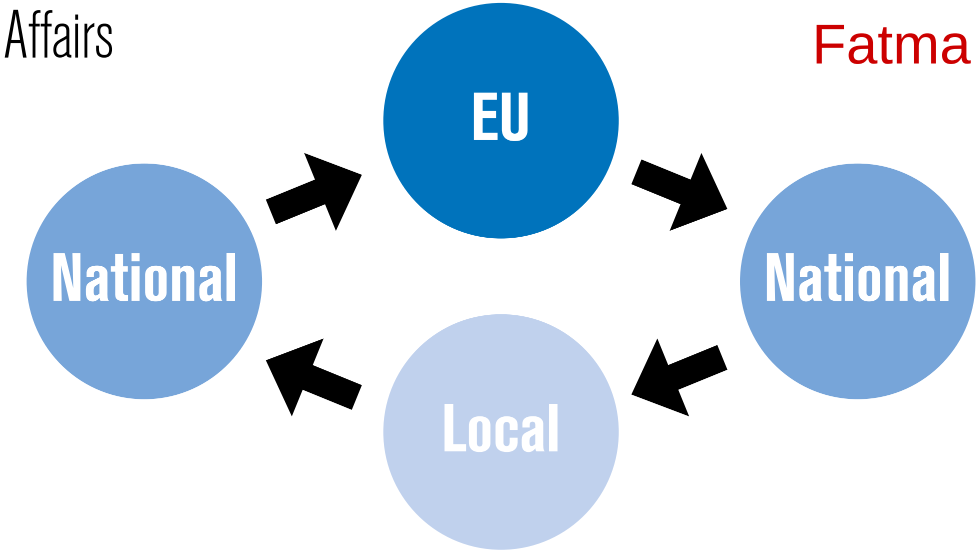

> EU policymakers in the European Council, the European Parliament and the European Commission use their position to make recommendations, publish road maps and fund certain projects in order to combat common health challenges, ranging from issues such as the ageing population to rare diseases.

Member States increasingly cooperate on health issues and see the need for EU level coordination as they are facing similar challenges. Activity at the EU level such as publications of studies, introduction of new European Commission initiatives or statements put forward by the European Parliament; create opportunities to build support at the national level on a specific issue.

HEALTH POLICY IN THE EUROPEAN UNION

To have an understanding of the relevant European and national policies underpins a successful advocacy campaign. Policy exists at many levels – the European level, national level and regional level. Dependant on your goal, the end result should be to increase your ability to influence, change and develop national policies so that your objectives are met.

It is always important to remember that your work at a local level impacts the national and even the European level. Starting at the local level provides a base for work at the national level. Likewise, advocacy campaigns at the European level may affect polices at national level and then the regional level. In other words, all actions are linked! A successful advocacy campaign not only looks at ‘what is going on at home’ but also acknowledges the different policies at the EU level.

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> CURRENT POLICY OPPORTUNITIES AND EU COMMITMENTS FOR PKU IN EUROPE

There are important developments happening across Europe which can serve as instruments and examples for your work. The fundamental point to any advocacy campaign is to understand and analyse the issues and policy objectives of importance to your national organisation. EU commitments serve as important reference points for national governments, therefore a brief knowledge of the background of the health policies surrounding PKUs at a European level would be an advantage.

The last couple of years have seen an increasing policy focus on addressing Europe's ageing population. In 2010, the European Commission committed itself to increase efforts in funding and coordinating investment to improve the sustainability and efficiency of national social and healthcare systems.

The EU has also focused on alleviating health inequalities and developing better healthcare delivery models; all issues which resonate with PKU patient organisations. Increased focus on chronic conditions and co-morbidities, greater needs in community and home care, better management of care and increased provision of aftercare services, healthcare professional and carer training, patient 'empowerment' and e-health solutions, all dominate health policy discussions in Brussels. >

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> SUMMARY OF OFFICIAL EU DOCUMENTS & COMMITMENTS

- European Commission White Paper (2007) Together for Health 2008-2013: The second health programme of the European Union identified rare diseases as one of the priority areas. Rooms for intervention that were highlighted include exchange of information via existing European information networks on rare diseases, and the development of strategies and mechanisms for information exchange and co-ordination at EU.

http://europa.eu/legislation_summaries/public_health/european_health_strategy/c11579_en.htm

- European Commission Communication (2008) on Rare Diseases: Europe's challenges: This Communication sets up a strategy to help member States in their handling of rare diseases, from diagnosis, to care and treatment.

http://ec.europa.eu/health/ph_threats/non_com/docs/rare_com_en.pdf

- European Council Recommendation (2009) on an action in the field of rare diseases: The Council recommends that member States adopt and implement National Action Plans on rare diseases in order to improve the situation of patients across Europe. An implementation report will be released by the European Commission at the end of 2013.

http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:C:2009:151:0007:0010:EN:PDF

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- European Commission

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Communication (2009) Solidarity in Health: Reducing Health Inequalities in the EU: A Communication highlighting the need for better collaboration with national authorities, regions and other bodies, in order to provide for better exchange of data and statistics of inequalities in the EU and on successful strategies to reduce them, including better provision of EU funding opportunities for national authorities.

http://ec.europa.eu/health/ph_determinants/socio_economics/documents/com2009_en.pdf

- Call for Tender: Evaluation of population newborn screening practices for rare disorders in Member States of the European Union (2009-2011): In July 2009, the European Commission organised a call for tender to evaluate newborn screening practices in member States (why a specific disease is screened, medical management and follow-up, etc.). A report of the experts committee will soon be available and could lead to the adoption of Council recommendations in 2012.

http://ec.europa.eu/eahc/health/tenders_H09C2.html

- European Council Conclusions (2010) on innovative approaches for chronic diseases in public health and healthcare systems: The Council Conclusions call on member states to develop patient-centred policies in the field of chronic diseases, as well as create new policies aimed at reducing health inequalities and to identify and share good practices to enable patients with chronic diseases to maximise their autonomy and quality of life. After public consultations were hold in 2011, the European Commission will be launching a reflection process on chronic conditions that will unroll throughout 2012, and possibly early 2013.

http://www.consilium.europa.eu/uedocs/cms_data/docs/pressdata/

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> en/lsa/118282.pdf

- European Parliament Resolution (2011) on reducing health inequalities in the EU: The Resolution calls on the Commission and National Governments to focus on the needs of vulnerable groups including people with disabilities, neurodegenerative diseases and patients diagnosed with chronic conditions and older people.

http://www.europarl.europa.eu/sides/getDoc.do?type=REPORT&reference=A7-2011-0032&language=EN

- European Commission Communication (2011) on Health for Growth Programme, the third multi-annual programme of EU action in the field of health for the period 2014-2020: The Health for Growth Programme is the third community health programme. In a constant effort to simplify procedures, the Commission suggests to put the focus on fewer actions, whilst improving coordination between member States. The Commission places the citizens at the centre and encourages member States to guarantee safer and better healthcare for citizens, which implies inter alia more support for rare diseases through European Reference Networks.

http://ec.europa.eu/health/programme/docs/prop_prog2014_en.pdf

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- European Commission Communication (2011) Horizon 2020 - The Framework Programme for Research and Innovation: Horizon 2020 is the funding programme of

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> EUROPEAN REFERENCE NETWORKS

The High Level Group on health services and medical care has been working on the concept of a European Network of Centres of Expertise since 2004.

Centres of Reference are a first step towards achieving European Networks of Reference. A Centre of Reference can be defined as “a place suitable for referring patients due to its expertise and scope of services”. The goal of Centres of References is to bring healthcare professionals and centres of expertise at national and regional level to exchange best practice and share knowledge. This will lead to better quality of and access to treatment for patients across Europe.

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Centres of Reference vary widely across Europe. Some countries have centres of reference that are dedicated to rare diseases (e.g. France, Denmark, Spain, and Sweden), others have set up centres of reference outside a specific rare diseases policy (e.g. Belgium, the UK) and some have no centres of reference at all (e.g. Cyprus, Germany, the Netherlands, Poland).

Likewise the definition of the missions of a centre of reference varies between countries, as does the definition of rare diseases.

It is recommended in a 2006 Rare Diseases Task Force report that, to avoid confusion, centre of reference should be named centre of expertise.

The Rare Diseases Task Force encourages funding of Network of Centres of Expertise at European level. The European Commission encourages information dissemination and communication between centres of expertise at regional, national and European level, in order to grant patients

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> the best quality of care possible. In 2008, the European Commission indicated that the Directive on patients' rights in cross-border healthcare ought to encourage Member States to facilitate the setting-up and development of European Reference Networks.

Centres of Reference for rare diseases in Europe: State-of-the-art in 2006 and recommendations of the Rare Diseases Task Force (2006)
http://ec.europa.eu/health/archive/ph_threats/non_com/docs/contribution_policy.pdf

Communication from the Commission on Rare Diseases: Europe's challenges (2008)
http://ec.europa.eu/health/ph_threats/non_com/docs/rare_com_en.pdf

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TOP TIPS...

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 which you can use later in your advocacy campaign and refer back to frequently.

> WHERE TO LOOK?

There are several ways to remain informed about relevant European and national health priorities. Here are a few sources of information you can begin with to start collating research, information and data that can help support your case:

- E.S.PKU website
- Other European patient organisations
- Local/regional and national institutes and universities
- Local/regional and national healthcare providers such as hospitals and health clinics
- Medical Journals
- Medical Publications
- Professionals and academics specialised in PKU
- Current national policies and plans

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

HOW TO ADVOCATE ACROSS EUROPE

Public health ranks high on the political agenda in the vast majority of countries and regions. As patient organisations have more knowledge and are more aware of how to communicate, they are increasingly more active and successful in promoting their demands to policymakers. These developments have contributed to an increased focus on patient centred care movements across Europe.

Advocacy is an important part of the decision-making process in Western Europe. Patient organisations are becoming more invaluable to decision makers. They offer solutions, expertise and often legitimise political decisions. Therefore, policymakers and

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> politicians are becoming more aware of the merits to engage with advocacy groups.

Advocacy in Central and Eastern European Countries (CEEC) is not understood to the same extent as in Western Europe. There is still a process of learning how to advocate effectively. However, due to the expanding influence of the European Union, policymakers from the CEEC are becoming more aware and open to advocacy groups. Patient groups should use their position as 'trusted sources' to build relationships with leaders in national governments.

USING THE EUROPEAN UNION

Understanding public affairs is important for your organisation to create awareness at a national level. You can demonstrate national leadership by taking EU policy-makers at their word and advocating policies and practices at the national level which link in to the core goals of the E.S.PKU. You can build momentum for change by referencing official EU documents which, by their very nature, are designed to be implemented in Member States. Your familiarity with EU policy and your ability to access such information quickly from your colleagues in Brussels can make you indispensable to national policy-makers or regional authorities, who may not have as much information and data at their fingertips. Therefore an understanding of Public Affairs in the European Union is vital for the successes of any national advocacy campaign. ■

TOP TIPS...

Always keep in mind the differences in the political cultures across Europe which can affect how you approach advocacy in your country.

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Annex III

Template Materials

Example of letter of invitation for a speaker at an event:

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[insert local member organisation logo] [insert partner/co-host/sponsor logo]

Date

Dear Dr. XX,

We are delighted to invite you as guest speaker to the [insert name of event, e.g. roundtable discussion] we will be holding in the [insert location] on [insert date of event]. The event will be hosted by XXX [insert host name, title]. This aims to bring together high-level representatives from the EU institutions and National Stakeholders, as well leading clinicians on the issue of how Europe can help people with the genetic metabolic disorder, Phenylketonuria (PKU), access better treatment and care across Europe [insert topic of event].

In this context, we would be delighted if you could attend our meeting as [professional title and place of practice] and provide a keynote speech on the importance of follow-up and aftercare, and the need for guidance provided at EU level for payers and providers.

As you know, the E.S.PKU launched a bench-marking report at their Annual Conference in Warsaw in October 2011, which compares the management of PKU in five EU healthcare economies, namely Poland, the Netherlands, Spain, Sweden and the United Kingdom. We strongly believe your insights and comments with regard to the [insert the host's country] system would be extremely valuable.

Some of the major challenges faced by people with PKU are unequal treatment (both in quality and access to treatment) within EU States and inadequate follow up and aftercare screening. These inconsistencies among EU healthcare systems in their handling of people with PKU and other metabolic genetic disorders can lead to and has led to despairing health inequalities.

As a reminder, the bench-marking report underlines the gaps in quality of care, support and treatment within European countries, unequal access to reimbursement, and calls for harmonised standards of care in Europe, including equal access to treatment and care, the need for international evidence-based guidance and more European research on PKU.

We will be highlighting the results from the report at the roundtable discussion, as well as acknowledging the obstacles and difficulties people living with PKU and other metabolic genetic disorders have to overcome throughout their lives.

We would be honoured if you could speak on this occasion and look forward to your reply. We will be following up with your office shortly to discuss your potential participation. We will provide a speaker's briefing along with key speaking points and detailed information on the roundtable discussion closer to the event.

Yours sincerely,

[Signature of local member organization] [EMAIL SIGNATURE]

With the support of

[Insert name of Member of Parliament]

Annex III Template Materials

Example of a Programme:

PROGRAMME

Title of meeting

Date
Time
Location

Moderator: XX, title

16:00 – 16:20	Title of presentation [Insert name, title, country of speaker 1] ▪ Talking points e.g. Disease Overview: Transmission, disease stages and mortality
16:20 – 16:40	Title of presentation [Insert name, title, country of speaker 2] ▪ Talking points e.g. Current policy challenges in PKU
16:40 – 17:00	Title of presentation [Insert name, title, country of speaker 3] ▪ Talking points e.g. Highlighting the need for appropriate standards of care in Europe: Follow-Up and Aftercare - the Need for European-level Guidance
17:00 – 17:30	Living with PKU: A Patient's Perspective ▪ Talking points e.g. personal story
17:30 – 17:55	Q&A
17:55 – 18:00	Wrap-up and Call-to action

Example of a Background Briefing:

CONTACT PROGRAMME:
[Insert contact name of local organisation]

Draft Itinerary (subject to change)

CONTACT DETAILS	
[insert name]	Tel: xxxx, Email: xxx

TUESDAY 28TH JUNE 2011

TIME	MEETING	VENUE
15.00-15.45	[insert name of Member of Parliament]	[insert address]
16.30-17.15	“	“
17.30-18.15	“	“

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Example of a Background Briefing (continued).

Esther de Lange (EPP/Netherlands)

Date: June 28TH

Time: 15.00

Venue: MEP Office

Assistant: Jos Van der Akker

European Parliament
Bât. Altiero Spinelli 12E146
60, rue Wiertz / Wiertzstraat 60
B-1047 Bruxelles/Brussel
Tel. : +32 (0)2 28 45954

Objectives

- Explore Mrs De Lange's **interest in PKU and playing an active** role in the highlighting this issue in the European Parliament.
- Assess Mrs De Lange's interest in putting herself forward to **be the EP Champion for PKU and to sponsor the European Parliament launch**
- Investigate the possibility if Ms. De Lange will organise a **workshop/parliamentary debate on the issue**
- Encourage Ms. De Lange to activate support **towards highlighting the issue of PKU in the ENVI committee**

Speaking Points

- Introduce Ms. De Lange to the issue of PKU- the differentiated approach to screening in EU member states
- Provide a general background information and context of PKU in the Europe – highlight the lack of attention which it has received in national health agendas and the lack of follow on support and treatment for PKU sufferers
- Raise the issue of inequalities between Member States on access to treatment
- Discuss the issue of fragmented approach to BH4 testing – in some EU countries the patient is tested whilst in others this is currently not possible.
- Go into specific detail on why it is important that policy makers must strive towards raising awareness of the disease and its impact on the patient vis-a-vis healthy life years.
- Place the issue of PKU in the European health trends- Active and Healthy ageing, chronic conditions, disability and rare diseases

(continues on next page)

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Example of a Background Briefing (continued).

- Inform Ms. De Lange of the European Benchmarking report – enquire if she would add a foreword
- Use the example of Holland as an example of a best practice country in terms of PKU screening.

Relevant information on Esther De Lange

Esther De Lange was born on 19 February 1975 in Spaubeek, NL. She holds a BA in European Studies, Institute of Higher European Studies (HEBO), The Hague (1993-1998) and an MA in International Relations, Brussels (1999-2001).

Since she was elected in the European Parliament in 2009, Esther de Lange has been a Member of the Environment and Public Health Committee.

In 2011, she advocated against a resolution on the ban of health claims made on foods and referring to children's development and health. As a young mother, she defended industry's position that claims should be permitted on foods for infants and young children as long as they are scientifically substantiated and that they meet all legislative requirements, and in 2010 she questioned the Commission on the setting of nutrient profiles in the Regulation on the nutrition and health claims made on foods.

She showed interest in health and ageing relating issues, and submitted in February 2011 a question on ways to improve medicine safety for older people. She also suggested the creation of a Geriatric Medicines Committee as part of the European Medicines Agency.

In 2009, she co-signed a Written Declaration "on excessive pressure to be extremely thin", calling the Commission to give more attention to eating disorders.

Mrs. De Lange is aware of the ES PKU following a previous meeting with members of Weber Shandwick. She showed considerable enthusiasm for the issue and is keen to learn more about the position of ES PKU in Europe. Her vocal and visible nature should lend to a positive meeting.

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Checklist

STEP	ACTIONS	ACTIONS	STATUS
1: Understanding the Issue	■ Search national databases for latest statistics on PKU ■ Reach out to your contacts at Hospitals, University, Publishing Houses to find latest studies on people with PKU	■ Initial research completed by end of March 2012	✓
2: Define Your Objectives			
3: Know Your Audience			
4: Message Development			
5: Identifying Channels for Engagement			
6: Identifying the Appropriate Tools			
7: Build an Engagement Plan			
8: Engage			
9: Maintaining Dialogue			
10: Measure Success			

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Frequently Asked Questions

WHEN SHOULD I START DEVELOPING AN ADVOCACY PLAN?

Once you have read the toolkit and understand the process, you can start brainstorming ideas and embarking on developing your own advocacy plan. It need not be a rapid process but rather a plan you develop step by step 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 further to tailor it to your needs at the national level. A good way to plan is to create a 'road map' for your organisation which is based on the 10 step long term engagement plan. You can then adapt it to timing and plot it over a period of 6 months to one year, taking into account key policy milestones which can help you raise your organisation's profile.

WHERE CAN WE FIND THE INFORMATION, DATA AND EVIDENCE WE NEED TO UNDERSTAND THE ISSUE?

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

- The ESPKU website: http://espku.org/
- National parent organisation websites 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 information on rare diseases, http://ec.europa.eu/health/rare_diseases/policy/index_en.htm

HOW DO WE DEVELOP A 'NETWORK' OF CONTACTS?

Patient organisations across Europe vary in terms of resources and capacity available to carry out effective advocacy. However, no matter how small or large your organisation is, you can always create, build and strengthen your network through first and foremost using informal channels such as family, friends, colleagues and support you

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receive in 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 see them as an on-going process which needs to be maintained and developed over a period of time.

HOW CAN WE IDENTIFY OTHER STAKEHOLDERS THAT CAN SUPPORT OUR ORGANISATION?

In order to strengthen your position and show that you know your issue and area well, it is good to connect and build relations with other third parties and non-governmental organisations which can support your efforts, for example, patient organisations representing people with rare diseases and chronic conditions. Other opportunities can be found in research and medical institutes. A simple internet search should give you many research.

WHAT HAPPENS WHEN OUR TARGETED POLICYMAKER LEAVES THEIR POSITION?

Having successfully identified the right policymaker for influencing and building a good successful relationship, it can be discouraging when a person leaves their position and we need to build relations with a new person taking over the policy area. However, this could be an opportunity to highlight your key issues to a new audience. The incoming policymaker may also have past experience and knowledge which can be useful when putting forward your case. It is important to find information on the new policymaker and identify gaps which you can address. For example, the new policymaker may have been working on cross-cutting issues such on health inequalities and may need further information about rare diseases. Alternatively, a new policymaker may have had personal experiences of dealing with PKU and therefore could be interested in the issue at a personal level. In any case, it is

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always a good idea to broaden your audience base and to garner relationships with a wide variety of policymakers.

WHAT HAPPENS WHEN THERE IS A SHIFT IN THE POLICY LANDSCAPE (E.G. ELECTION OF A NEW GOVERNMENT)?

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 which can have a large effect on the national healthcare system, it is a good time to re-evaluate 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 further support. In these situations, it is best to take your current advocacy plan and identify the key sections which need to be adapted taking into account the new landscape. For example, you may need to remap your priority stakeholders.

WHERE CAN I GET MORE HELP IN UNDERTAKING AN ADVOCACY PROGRAM?

One of the crucial points to remember when developing and rolling out your advocacy campaign is that other patient organisations in Europe are dealing with similar objectives and may have information and experience that can help you. E.S.PKU may be able to help provide support by providing information and best practice examples in Europe. If you need help or guidance please contact info@espku.org ■

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Useful Links

EUROPEAN SOCIETY FOR PHENYLKETONURIA AND ALLIED DISORDERS TREATED AS PHENYLKETONURIA (E.S.PKU)

www.espku.org/

E.S.PKU ASSOCIATED ORGANISATIONS

- PKU Board
- European Organisation for Rare Diseases [Eurordis]
- National Organisation for Rare Disorders [Nord]
- European Platform for Rare Disease Registries [EPIRARE]
- European Patients' Forum [EPF]
- European Genetic Alliances Network [EGAN]
- European Platform for Patient Organisations, Science and Industry [EPPOSI]
- European Medicines Agency [EMA]
- Committee for Orphan Medicinal Products [COMP]
- EuroHealthNet
- European Alliance for Access to Safe Medicines [EAASM]

EUROPEAN COMMISSION – HEALTH

http://ec.europa.eu/health/
http://ec.europa.eu/health/major_chronic_diseases/policy/
http://ec.europa.eu/health/rare_diseases/policy/
http://www.eucerd.eu/

EUROPEAN COMMISSION – RESEARCH

http://cordis.europa.eu/home_en.html
http://ec.europa.eu/eahc/health/

EUROPEAN PARLIAMENT

http://www.europarl.europa.eu/

FACEBOOK

SHS-PKU Community
International PKU Adults Meeting
Patient Power PKU

INDUSTRY SPONSORED WEBSITES

http://www.pku.com/en/index.html
http://www.nutricia.com/
http://www.pkuworld.org/home/home.asp

SOCIETY FOR THE STUDY OF INBORN ERRORS OF METABOLISM

http://www.ssiem.org/home/welcome.asp

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Glossary

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, and represent their interests and obtain services they need

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

BRIEFING
A document providing a brief background on an issue/topic (e.g. briefing on inequalities of access to treatments for persons with PKU)

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 (e.g. members of parliaments)

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

ERA
European Research Area.
On 18 January 2000 the European Council (EC) issued a communication entitled 'Towards a European Research Area' that proposed ways in which research in Europe could be more effectively organised and co-ordinated

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> ERC

The European Research Council, which is the Ideas Specific Programme of FP7, is worth over €7 billion from 2007 to 2013. The ERC funds investigator-led, frontier research. It largely consists of two grant schemes, the Starting Independent Researcher Grant and the Advanced Investigator Grant

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

ESF

European Science Foundation

ETP

European Technology Platforms are stakeholder groupings, led by industry, that help to 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 which have been voted on by the heads of states of EU Member States; 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 Council consists of the Heads of State or Government of the Member States, together with its President and the President of the Commission

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Annex VII Glossary

> THE EUROPEAN COMMISSION

The EU's executive (civil service): proposes and enforces legislation

THE EUROPEAN PARLIAMENT

Body of national representative politicians; amends and approves legislation jointly with the Council of Ministers

EUROPEAN PARLIAMENT RESOLUTION

A non-legislative report published by MEPs which focuses on a specific issue/topic

EXECUTIVE SUMMARY

Executive summary is a term used to describe an overview of a longer report or proposal in such a way that readers access the information quickly

FP (FP5, FP6, FP7)

The EU's Framework Programme for Research and Technological Development. The Fifth Framework Programme (FP5) was adopted in 1998 and ran until 2002, with FP6 then running from 2002 to 2006, and FP7 running from 2007 to 2013. The budget for FP7 is over €50 billion. It is made up of seven Specific Programmes: Co-operation; Ideas (implemented through the European Research Council); People (the Marie Curie Actions); Capacities; the Joint Research Centre (JRC); Euratom and the JRC implementing Euratom

FP 8

The 8th Framework Programme (FP8) will provide the base for the Europe 2020 Flagship Initiative Innovation Union and help meet major societal challenges with a proposed budget of at least 140 billion €

GOVERNMENT OFFICIAL

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

IDEAS

Ideas is the second Specific Programme of FP7 worth over €7 billion from 2007 to 2013. New to the Framework

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Programme, Ideas will fund investigator-led, frontier research. It is implemented through the European Research Council and consists of two grant schemes, the Starting Independent Researcher Grant and the Advanced Investigator Grant

ITRE

The European Parliament Committee on Industry, External Trade, Research and Energy (FP7)

JRC

The EC's Joint Research Centre acts as a scientific and technological laboratory in support of EU policies, with a range of institutes and research activities

MEPS

751 elected representatives (MEPs) from all the member states

MESSAGES

Advocacy messages are used to convince and influence people and policymakers in order to achieve the desired objective

MONITORING

Closely following a particular policymaker, stakeholder or cause/issue/topic/news

NATIONAL COMPETENCY

The ability to have responsibility and power over particular internal polices and political agenda without foreign consultation

NON-GOVERNMENTAL ORGANISATIONS

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

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> ORGANIGRAM

An organisational chart is a diagram that shows the structure of an organisation and the relationships and relative ranks of its parts and positions/jobs

OUTCOME EVALUATION

The outcome is the concrete results of your engagement activities (e.g. change in national policy)

OUTPUT EVALUATION

The output evaluation is when you measure how much you have achieved vis-à-vis how much you had planned to accomplish

OUTTAKE EVALUATION

The outtake is the impact of your engagement activities on the policymaker (e.g. their perception of your member organisation (MO))

PARLIAMENTARY COMMITTEE

One or more policymakers who specifically deal with certain issues so that they can investigate and examine and report back to the wider group

PEOPLE

The third Specific Programme of FP7 is worth over €4 billion during the period from 2007 to 2013. Made up of the Marie Curie Actions, it aims to improve the quality of human resources in European research through training and trans-national mobility of researchers

POLICY

Policy is defined in the Oxford dictionary as “a plan of action adopted by a person or organisation.” E.g. a policy on health, transport, finance or relations with another country

POLICYMAKER

A person who helps to form policy as part of their profession (e.g a civil servant); policymakers can include decision-makers

POSITION PAPERS

A document outlining your MO’s specific position/thoughts/ opinions on an issue/topic 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, public and private, 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

SICA
Specific International Co-operation Actions are FP7 call topics where a partner from an ICPC country has to be involved

SPECIFIC PROGRAMME
FP7 is made up of seven Specific Programmes: Co-operation; Ideas (implemented through the European Research Council); People (the Marie Curie Actions); Capacities; the Joint Research Centre (JRC); Euratom and the JRC implementing Euratom

TOOLS
A set of instruments used to achieve your objectives: conferences, surveys, EU policies, position papers etc…

TRACKING
Keeping informed about a certain issue, monitoring engagement and recording outcomes

TRANSPARENCY
Transparency is openness, communication, and accountability of an organisation

WHITE PAPER
A white paper is a non-legislative authoritative report or guide that guides policymakers in solving problems. White papers are used to educate readers and help them make decisions

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