FACTSHEET 11

Guide to Patient Advocacy

ENGAGe

ESGO | European Network of Gynaecological Cancer Advocacy Groups

The European Voice of Gynaecological Oncology

Foreword

Gynaecological cancers, such as those of the ovaries, cervix and womb are among the most common cancers to affect women. Yet they are often silent, because they do not attract the attention they deserve from the general public, health policy-makers and women themselves. Patient organisations across Europe are working to break this silence to improve the prevention, screening, treatment and care of gynaecological cancers. As the voice of European gynaecological oncology, ESGO shares these goals with patient organisations.

ESGO strives to empower gynaecological cancer patient groups, helps create groups in countries where none exist, and facilitates networking and collaboration between patient groups. The overarching aim is to support patient groups, but also to promote awareness about prevention, timely diagnosis and access to quality care for all women in Europe who have, or have had, gynaecological cancers (including ovarian, uterine, vaginal, vulvar, endometrial or fallopian tube cancers).

Following the recommendations from the 1st ESGO patient seminar, ESGO launched ENGAGe – the European Network of Gynaecological Cancer Advocacy Groups — in 2012. The objectives of ENGAGe are:

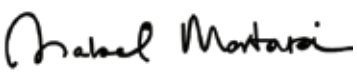
- Facilitate the development of national gynaecological cancer patient groups in Europe and to facilitate networking and collaboration between them.
- Disseminate information and share best practices to empower patient groups and improve the quality of care across Europe.
- To increase patient representation in ESGO activities by education on current research and health policy.
- To advocate patient care policies practices and access to appropriate care at both national and European levels.
- To educate patient groups, health professionals, the public and health decision makers.

The 2nd Patient Seminar *Gynaecological Cancers in Europe: Patient Advocacy & Collaboration*, organised in Liverpool in 2013, is dedicated to the theme of advocacy, which is why this advocacy toolkit has been developed.

By working together, both amongst patient groups and with ESGO, we can pool expertise and best practice, disseminate information, and educate stakeholders. These comprise patient groups, health professionals, the public and health decision-makers with which we can focus on cancer risk and good practices in gynaecological cancer care, including the organisation of cancer care, psycho-social support and multi-disciplinary cancer care.

Together, we must work tirelessly to reduce disparities which exist across Europe, to improve awareness and prevention as well as patient involvement in the process of diagnosis, treatment and the quality of care. However there are challenges ahead so patient-driven groups can become strong advocates at both national and European levels for improved patient care policies and practices. We hope this guide will stimulate collaboration and partnerships to strengthen the collective voice as well as advocacy initiatives, which will bring about progress and change.

John Green,
ENGAGe Chair



Isabel Mortara,
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Introduction

Why is patient advocacy necessary?

Nothing is as strong as the real patients' voice when priorities are being set in healthcare. With patient involvement increasingly recognised as a key component in the redesign of healthcare, the timing has never been better for patient organisations to make the voice of women with gynaecological cancers, their loved ones and those at risk of developing the disease heard among health decision-makers, and those whose cooperation you might need to influence them. Since healthcare systems, government screening and prevention programmes as well as access to therapies are increasingly under scrutiny in terms of value for money in many countries across Europe, there has never been a time when health policy-makers need more convincing arguments of the patient's true needs articulated through strong and compelling arguments to help them take the right decisions.

How to use this advocacy guide?

This guide is divided into ten sections, which explain step by step how to plan, prepare, conduct and monitor your advocacy efforts. It is important to remember that one size does not fit all, so the guidance and tips provided should be adapted to your national circumstances, organisational structure and available resources.

If you are creating an advocacy plan for the first time, we would encourage you to go through the manual step by step. If you are, however, an experienced advocate interested in some parts of the guide you should be able to navigate through it easily to focus on those parts you need most without necessarily reading the whole document.

Indeed, for those of you already engaged in advocacy, the guide can help you strengthen your plans. It does not mean that you need to start from scratch. On the contrary, you should build on your work to date to see whether your efforts can be streamlined and enhanced based on the guide.

We hope you find this guide useful and wish you good luck with your advocacy efforts!

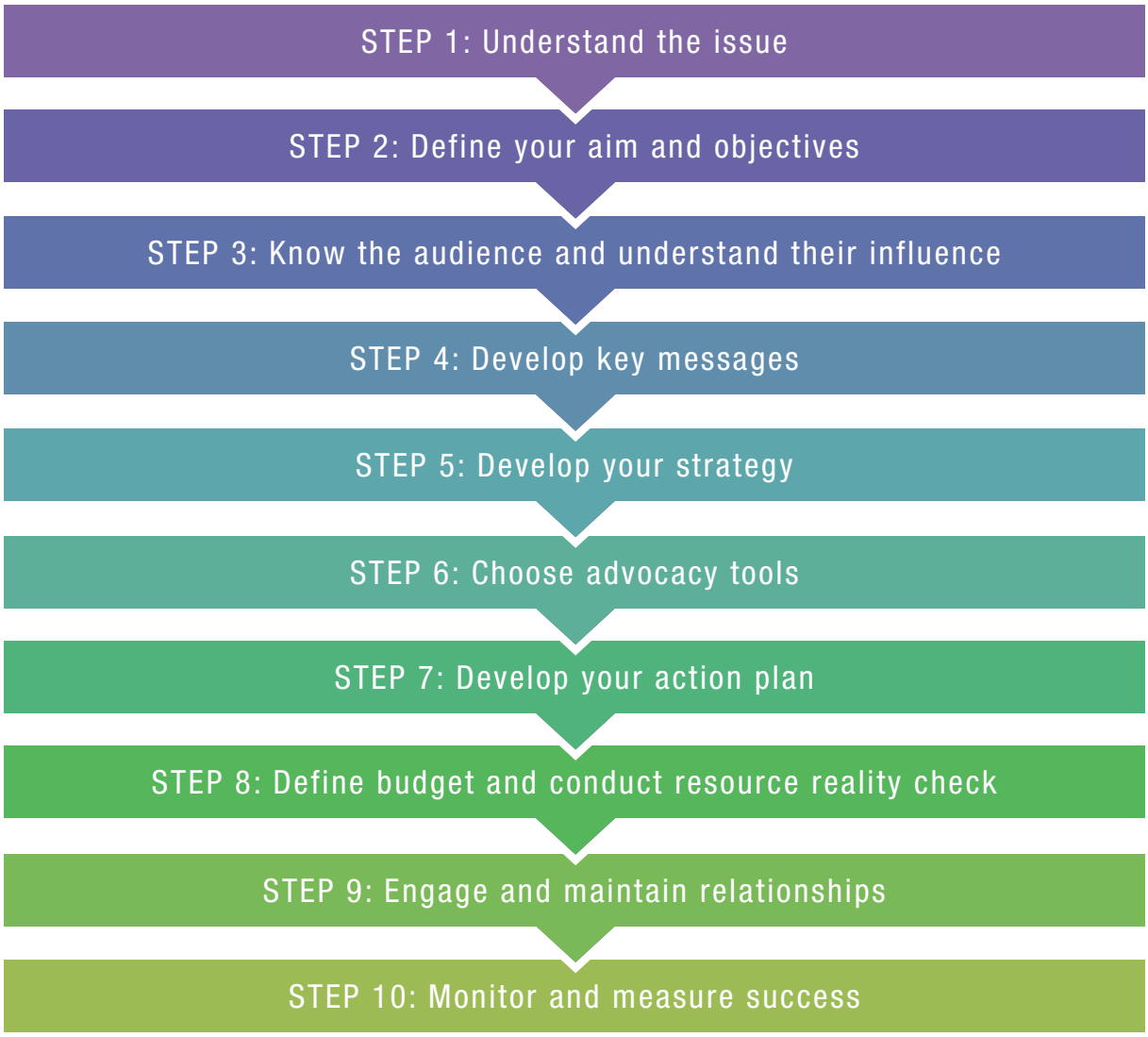
What is advocacy?

Advocacy has become a 'buzz word' for a set of skills and activities used to mobilise the necessary resources and forces to support an issue and create a shift in policy-making to support a position you believe is right.

The goal of patient advocacy is to put patients' needs at the centre, to make sure all health care is focused around the patients' true benefit, and that patients are respected as equal partners in all decisions about them, following the motto "Nothing about us without us".

How to develop an effective advocacy campaign

Several steps are required to develop an effective advocacy campaign, as shown in the diagram below. Each step is then explained on the following pages



STEP 1 - Understanding the issue

No lack of issues for patient groups to tackle?

Cancer care and research have progressed greatly over the past decades, but this regrettably does not apply to all cancer types and there are large numbers of critical issues that gynaecological cancer patient organisations across Europe have to address. Rarer gynaecological cancers get less attention from science, research, industry, the media and the health community. Moreover, information about scientific progress in the area of gynaecological cancers does not always reach all segments of the public. Large differences still exist both between and within European countries regarding cancer risk, detection and treatment. Many European countries do not have effective cervical cancer prevention programmes and even if they do, many women are not aware of their importance and so they do not use them.

Important for you, but is it also relevant for others?

Any successful advocacy plan is based on a thorough understanding of the issues and on-going policies related to them. Before defining your objectives, you need to establish not only what is important for you, but also what is relevant to health policy-makers or at least whether there is a health policy angle allowing you to make it relevant to them. While you are gathering information, you should also keep track of organisations or professional bodies who might share your concerns and goals, e.g. patients groups with different gynaecological cancers or other cancers more generally, gynaecological oncology specialists/societies, cancer leagues, nurses, charities and industry.

What's most important for patients?

Start by carrying out a short analysis of the issues important for gynaecological cancer patients, taking into consideration factors such as the credibility of your patient-led group to engage on the issue, how urgent the issue is for patients or whether you have sufficient resources to have an impact. In some countries, the power/resources/legitimacy resides with government and in others with national societies and charitable and/or patient organisations.

The table on the right is an example of how such a checklist might look. It needs of course to be adapted to your issues and the cancer area you are working on.

To trigger ideas of possible issues the ESGO Report Patient Seminar – The patient perspective: gynaecological cancer in Europe (September 2011) provides insights from a range of different patient groups.

How do patient priorities match those of health policy-makers?

Knowing what is important to patients is only half the picture in establishing the issues that your advocacy plan is going to focus on. You also need to understand what is important for health policy makers and other external groups who are or could be influencing their decisions. To advocate with health policy makers, patient organisations need absolute clarity on what they want, why they want it, and why it is the right way for health policy makers to go.

You can gather background information through a desktop research, but also through informal conversations with a number of carefully chosen stakeholders. The purpose of this exercise is to understand:

- Are any of your issues already on the health policy agenda? Are they likely to be there in the near future? Why yes/not?
- Are there any relevant initiatives on the European/ international level that might impact the national agenda?
- How do health policy-makers feel about the issue?

Issue (examples)	Desired Outcomes	Power/ Resources	Legitimacy	Urgency
A. Lack of nationwide cervical cancer screening or vaccination programmes	e.g. Quality assurance in cervical cancer prevention & screening	Where does decision-making power reside? How can the necessary measures be funded?	What is your legitimate role in the decision making process and which other stakeholders are concerned?	What will happen if no action is taken?
B. Lack of adequate training for health professionals	e.g. Multi-disciplinary approach with wide mix of trained professionals			
C. Lack of referrals to specialised centres	e.g. Guidelines for minimum number of patients to be treated by individuals			
D. **Insufficient quality of care**	Access to quality care for the majority of the population			
E. **Lack of recognised patient-reported outcomes such as pain, depression, fatigue....**	e.g. Recognition and treatment of symptoms			

Do we understand enough about the health policy making process affecting these issues?

- How is the current health policy formed?
- Who influences health decision-makers?
- What is the political/process timeline and at which stage are we at the moment?
- Are there any other organisations advocating for the issue?

Below you will find a shortlist of possible information sources to help you with your desk research, which can be done online by consulting websites, newsletters and campaigns, as well as media publications & medical journals. You might want to check:

- Other ENGAGe network members and other cancer patient groups (http://esgo.org/ENGAGe/Pages/NetworkMembers.aspx)
- Local, regional and national institutes as well as universities
- Local, regional and national healthcare providers such as hospitals and health clinics
- Professionals and academics who specialise in gynaecological cancers
- Current national and European policies or plans.

Are you ready to prioritise and chose the 2 to 3 issues that your advocacy plan will focus on?

Once you have completed your research and answered the questions mentioned above, you can prioritise the issues by comparing the priorities of health policy makers and other people who influence the gynaecological cancer agenda with your internal issues list. This should help you choose those that are important for you and also (potentially) timely and relevant for people you want to influence through your advocacy plan.

At the end of this exercise, you should have no more than two to three priority issues, which should allow you to focus resources to achieve better results.

It may happen that your priorities will include an identified gap that needs to be addressed. Don't lose sight of this, as it will be important for the strategy you will be working on later on under STEP 5.

TIP

Think not only about health policy makers but also other relevant stakeholders, whose agenda might touch upon your issues, e.g. gender equality, women's rights, research & development, rare cancers etc.

STEP 2 - Defining your aim and objectives

Your objectives are crucial to a successful outcome

Once you have gained a clear overview of the issues, it is time to define the aim and objectives of your advocacy campaign.

Don't get too caught up in the terminology. Think of your aim as the long-term result that you are trying to achieve on behalf of gynaecological cancer patients and those who are close to them – it's your big idea for your advocacy campaign. The objectives are the things you will have to accomplish through advocacy in order to achieve your aim.

The examples below illustrate this relationship in practice:

	Aim	Objective
Example 1	Prevent gynaecological cancers through public education, screening programmes and vaccination	1. Increase cervical cancer screening and policies to screen at-risk women for cervical cancer and achieve optimal coverage (according to best-practice recommendation as well as policies and optimal coverage for HPV vaccination) 2. Identify BRCA risk families and establish programmes
Example 2	Advocate for more research into new treatments for less common cancers affecting women	1. Increase recognition of the value of targeted therapies by governments (national and EU) 2. Increase collaboration with rare cancer networks and contribute to sharing the patient voice with EU decision-makers 3. Increase opportunities for patient involvement in research, such as contributing tissue and blood samples.
Example 3	Ensure that multi--disciplinary treatment and truly holistic care of gynaecological cancer is the norm for patients.	1. Drive changes in national health policy and guidance, placing the gynaecological oncologist and care team at the centre of collaborative, multi-disciplinary cancer care. 2. Increase awareness of the need for more funding to support the work of clinical nurse specialists as a key point of contact for gynaecological cancer patients; the need for psycho-social care and professional education, the coordination of the multi-disciplinary team, and acting as advocates for women and their families. 3. Increase or defend good practices in gynaecological cancer care – tailored to specific local situations and needs.

SMART objectives

All objectives must be Measurable; that is why objectives always start with an action verb, one that can be observable and measurable. It describes what you are expecting to do:

- Increase, decrease
- Continue, maintain
- Eliminate, remove
- Protect, defend.

The objectives must be related to things that you can influence. If the change desired from the objective is mainly something that depends on others, take another look at it and make sure it is Specific enough and Attainable.

Relevant and **T**ime-related aspects of the objectives should be understood (but are not always stated in the written objectives) as this information will be essential to drawing up your strategy and action plan.

Look for synergies

Build alliances with other patient organisations, with umbrella organisations, and refrain from demonstrating rivalry. Patient organisations need consensus and unity among their membership on the lines to take – without this a 'divide and rule' approach is an easy option for health policy makers to take. Patient organisations need to decide on a case-by-case basis when to advocate for their own disease and when better to address the broader picture in alliances across diseases, e.g. in collaboration with other patient organisations or umbrella networks. It is worth remembering that health policy decisions are often not made to address *disease-specific* needs!

Build alliances also with professional societies. It may be important to keep in mind ESGO's wider European objectives (see box for some examples) to achieve synergy across Europe. Given limited resources, think about how you can link your objectives to ESGO's work but also to the work of other stakeholders and potential partners to build on their work.

ESGO AIM

- Overcome taboos and reduce stigma
- Highlight the role of patient organisations

ESGO OBJECTIVES

- Increase public awareness
- Improve evidence-based health policy making
- Increase opportunities for patient involvement in research
- Improve professional education and promote a multi-disciplinary approach
- Increase and defend good practice in cancer care
- Increase synergies across geographical divides

Don't forget to measure and evaluate

Finally, make sure that you think from the outset about how you will measure and evaluate the campaign. This is not only useful in terms of explaining what you are doing, but it will also help you to better understand where you are being successful and where you may be falling behind. With this information, you can adapt your strategy or review your objective if needed. You will find some useful tips related to monitoring and measurement in STEP 10.

Use the SMART rule for focused and effective advocacy.

- Specific – targeting a specific area for improvement.
- **M**easurable – quantifying or at least suggesting an indicator of progress.
- **A**ttainable – stating the results that can realistically be achieved given available resources
- **R**elevant – ensuring that what we want to achieve does matter
- **T**ime-related — specify when the result(s) can be achieved.

STEP 3 – Knowing the audience and understand their influence

So many people, so little time – How to decide who really counts to deliver on your objectives?

Once you have defined your objectives and you know whether to raise awareness or to secure funding, you must outline your audience base. In simple terms, this can be split into health policy-makers who are in government or involved in implementing government health policy (regional, national, and European) and non-health policy-makers such as media representatives, academics, medical experts, think tanks, other patient groups, or local communities etc.

The purpose of analysing the target audiences for your advocacy plan is to:

- Identify the people you will need to ultimately convince in order to achieve your objective, (called potential partners) and also the people who will help you convince them (called potential influencers)
- Understand where these people stand in terms of the objective you are trying to pursue and if they are positively disposed – while also assessing how much influence these people have.

By going through the process in a rigorous manner, you will gather a great deal of information that will be essential for your plan; and you will save yourself the trouble of putting resources into targeting a government department, minister, or healthcare provider who might not have the power to help you, or is not willing to.

Four steps to scope out your target partner/ influencer audiences

1. Identify: find your relevant groups, organisations, and people – you need their names, titles and functions
2. Analyse: understand your stakeholder's views and interests
3. Mapping: make a visual overview of your stakeholders and their issues
4. Prioritise: rank stakeholder and issues – ideally you will have identified no more than 10 to 25 and you will need to have their full contact details.

1. Identify: how do you know your target?

Some examples of questions you could ask yourself to help identify the people you need to target:

- Beyond patients, who are the people affected by a lack of attention for gynaecological cancer?
- Who has the power to make decisions about gynaecological cancer?
- Who influences these decision-makers?
- Who decides on the budget for gynaecological cancer care?
- Who might share our objective outside of the gynaecological field?

2. Analyse: understand your stakeholders

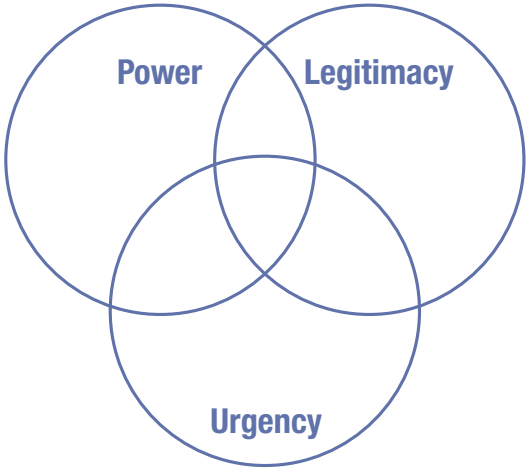
After identifying the possible stakeholders, you will need to analyse them to better understand their perspective, their relationship with the issue and their power to initiate or support reforms. Answering some key questions about your identified stakeholders could help you with this:

- What position do they have on the issue (are they for or against reform)?
- What is their interest in reform?
- What is their power or influence on this issue?
- What is their potential to affect, or to be affected by, policies and institutions?
- Which group coalition do they belong to, i.e. what are their relationships?

TIP

Think beyond your ministry of health. Who is for example responsible for gender issues?

3. Mapping: visualise your stakeholders



By this stage, you need to see the "wood for the trees". You will have lots of names and organisations and you'll be seeking to understand how you can align them with your objectives.

An effective way to do this is to draw up a diagram which tracks many of the questions you've asked when you were analysing the stakeholder. Look at each one and place on the diagram according to:

- The power they have to either help or hinder you in reaching your objective,
- The credibility and legitimacy to influence the outcome in relation to your objective,
- The drive or urgency they have to help you achieve or hinder your objective.

Once they are mapped, you will see which stakeholders are important to you (they have legitimacy and power) but possibly don't see your objective as urgent – so your strategy will have to take this into account. The target audiences that meet all three criteria will definitely be important to you.

4. Prioritise: rank stakeholder and issues

Now is the time to write down your list and identify who are the "must" involve people, and who are just "nice" to have on board. Keep it manageable - ideally you will have identified no more than 10 to 25 stakeholders and you will need to have their full contact details.

Don't forget Europe!

Effective advocacy plans at national level will also contribute to European advocacy. EU officials are rarely completely cut off from their country of origin and will always be more interested in initiatives taking place in their country of origin. In addition, Members of the European Parliament have the duty to reflect their electorate, so they maintain even closer links to their country of origin. Finally, experts for example those that sit on the European Medicines Agency have a dual role – both national and European.

You will most likely find that your target audiences fall into a number of these categories.

- ESGO members
- Women with gynaecological cancers in your country and their families and friends
- Other patient organisations involved in cancer, gynaecological cancer societies and cancer leagues,
- Local, regional and national institutes and medical universities
- Local, regional and national healthcare providers
- media: TV, radio, blogs, social media sites, publications such as medical journals, women's magazines, weekend supplements, health columns, etc.
- Health policy makers involved in national policies and plans etc.

STEP 4 – Developing key messages

Now that you know with whom you want to engage, it is important to make sure that you have the right messages in place to communicate your objectives.

Explain your objective

Start with developing an overarching message that reflects your advocacy position and is slanted towards the interests of the receiver. It is your "story in a nutshell". Imagine that you meet a very important stakeholder for your cause - e.g. the Minister of Finance - who has just one minute for you. How would you pitch your cause to him/her?

Once you are clear about your story you can then develop three to four key messages, which will follow the overview but will tell your story in more details. There are different ways of telling the story (e.g. starting with the past, explaining the current situation and looking into the future). However, as you are advocating for a concrete cause and want your audience to understand what you expect from them you might want to follow a different pattern:

- What is the challenge OR What do you want to achieve
- Why you want to achieve it (the benefits of taking action, and/or the negative effects of doing nothing)
- How you propose to achieve it
- What action you want the target person to take.

It is important that where possible your key messages are backed up by 'proof points' – facts, figures but also anecdotal evidence or "word pictures", which bring them closer to life (e.g. *the number of women suffering from XXX cancer in Europe is similar to the population of XXX city*) . Your message will then become much more persuasive and will address the questions your audience may ask having heard your messages.

Make your audience care

The messages you develop should become the basis for all your communication efforts. While emotional messages may create impact, underline it with substantive credible, scientific or anecdotal evidence wherever possible. You need to bear in mind that, although your messages might make perfect sense to your organisation, it does not necessarily mean that they will automatically resonate with your audiences. Therefore you need to tailor your messages to their needs, expectations and interests.

A simple way to do this is to put yourself in your audience's shoes and try to understand what might be interesting for them in your story. Make use of the analysis of the stakeholders of STEP 3. Key questions that can help you mould an effective message are:

- What group of people does the audience represent?
- What is the knowledge of the audience, what do they already know?
- What is their (political) position?
- What is likely to persuade this audience?
- What kind of information matches this message?

Once you understand these expectations, tailor your messages to them e.g. by choosing relevant sub-messages and proof-points.

If you are targeting the Ministry of Finance you will need to bring in economic/financial arguments. This will involve getting help from the right people to develop your key messages.

Different audience = different needs

- **Civil servants**: problem solving, efficiency
- **Ministers:** political narrative, impact on national constituency, cost efficiency
- **Members of the Parliament:** constituency, personal interests, fairness, career progression
- **Media:** headlines, personal patient stories and impact on society

Keep it clear and simple

Last but not least, keep it clear and simple. For an advocacy message, no matter if it is spoken or written, clarity is fundamental. Avoid jargon and stick to 3-4 key messages that themselves can be communicated in a few simple sentences.

TIP

Focus on no more than 3 messages, that can be summarised in 3-4 four key sentences

STEP 5 - Developing the strategy

Why is developing a strategy necessary?

Once you know your objectives, audiences and message you want to convey, it's time to decide on your strategy. The strategy will help show in broad lines how the objective is going to be achieved. It indicates trade-offs and choices you have taken to make the best possible use of your available resources. It is also important that your organisation can explain succinctly what it's about and how you are going to do it. The key building blocks to doing this are:

- Aim – maximum 2
- Objective – maximum 2 per aim
- Strategies – maximum 2 per objective.

It should be possible to fit it all onto one PowerPoint slide or side of A4.

Example how your strategy fits into the overall advocacy campaign

- The aim: "help women with gynaecological cancers obtain accurate, reliable and timely information about their disease" and timely access to best possible guide to care,
- An objective: "to increase diagnosis and reduce treatment delays"
- A strategy: "by working with other patient cancer groups and ESGO to make the case to government to fund and initiate a cancer registry in my country".
- Selecting this strategy will shape how you will go about implementing your advocacy plan and implies:
  - Working in partnership,
  - Identifying existing peer reviewed articles or writing them and/or best practice and positive outcomes achieved in other countries,
  - Identifying committed patient advocates and experts and asking them to rally to the cause,
  - Instigating a series of meetings and events may be needed to galvanise the different partners around this cause,
  - Using the media to put pressure on government to make this a priority and allocate the funding or indeed create the conditions for a public-private partnership.

The simple way to get started? Try answering the following questions:

- What resources and assets exist that can be used to help achieve the objectives?
- How can they be used best?
- What obstacles exist that could make it difficult to achieve your objectives? How can you minimise or get around them?
- Is it better to advocate alone or in a coalition with a partner(s)?
- What are relative advantages and disadvantages of using different approaches or combination of approaches e.g. capacity building, institutional strengthening, research, advocacy, networking, etc.?

Advocating alone or with others?

In some cases a collation of organisations advocating for the same goal may be more effective than isolated efforts, especially if your organisation has limited resources (be it human, skills or financial).

Coalitions can be short or long term, they might be formalised through an official agreement or indeed informal. Whatever the case, they will require from you some time and energy to develop a relationship based on trust and mutual involvement.

TIP

The strategy generally starts with the word "by" followed with a verb. It will then go on to describe the game plan to reach the objective.

When you are looking for partners, check first the organisations with an agenda that can be similar to or complementary with yours. You might want to take into consideration the following options:

- ESGO members in your country and leagues or professional societies
- Clinical research groups/investigator groups/study groups
- National gynaecological cancer patient groups or cancer leagues
- Other organisations representing people affected by cancer (e.g. in case of objectives related to cancer patient care) in your country
- International umbrella patient organisations (e.g. all-cancer groups, or international networks in your specific disease area)
- Appropriate partnerships with industry with carefully defined areas
- Supportive national government officials who can make your case from inside
- Non-governmental organisations dealing with equal rights issues

Bear in mind that there might sometimes be an overlap between your potential allies and people you identified as influencers, and that health policy decisions are mostly not made on a disease-specific issue.

STEP 6 – Choosing advocacy tools

Plenty to choose from but which are the best for you?

Your selected methods and approaches to advocacy work will be influenced greatly by a country's government and health system. There are no simple rules for choosing the best advocacy methods. Your choice of the best advocacy tools will depend on many factors:

a) the target person/group/institution;

b) the advocacy issue;

c) your advocacy objective;

d) the evidence to support your objective;

e) the skills and resources of your coalition; and

f) timing – for example, external political events, when a law is still in draft form, immediately before a budgeting process, time of year, stage of advocacy process

It's all in finding the right mix

It can help to think of tools falling into 5 main groups. However, in practice an advocacy strategy would involve a variety of tools from some or all of the groups below.

1. Directly Influencing Health policy: position papers, working in the system (e.g. participation of patient advocates or experts on ethics committees, commissions and working groups), writing letters, submitting petitions and meetings with health policy-makers, study visits.
2. Monitoring/engaging Government and Regulatory Processes: releasing clinical trial data, or figures on R&D funding, submitting information as part of public consultations set in place by government. This area will require on-going Intelligence gathering and monitoring.
3. Providing Information and Training: reports to measure/compare one part of a country with another or across the EU (e.g. if your objective is to increase funding for multi-disciplinary treatment by sharing comparative data collection), website equipped with information for others to use in advocacy, inviting key decision-makers to speak at conferences/ meetings, organising or partnering in workshops for decision-makers to engage with other groups (to learn from each other), providing guidelines and input for training materials (e.g. for medical students), release statements and declarations, e.g. consensus statement on signs and symptoms of gynaecological cancers.
4. Demonstrating Good Practice: Partnering with other stakeholders to trial pilot schemes, other opportunities exist through public private partnerships (e.g. to initiate cancer registries that include high-quality stage, treatment and survival data on all patients).
5. Public Education and Awareness Raising: Media including press releases, opinion pieces, contacts with journalists, profile raising and fund raising events, days to put the spot light on key issues (e.g. World Cancer Day – 4 February; International Gynea Awareness Day – 10 September, World Ovarian Cancer Day will take place on May 8, International Women's Day 8 March, Rare Disease Day 28 February), online forum for patients to share experiences, celebrity support and campaign gimmicks (e.g. wrist bands).

Example: objective to promote good practice in gynaecological care

The main advocacy tools will revolve around communications that demonstrate::

- what good practice looks like = case studies
- cost effectiveness with health economics = commissioned reports
- performance by measuring or comparing in order to single out best in class = score-cards or report-cards
- the impact on quality of life = patient and expert testimonial.

Each of these tools has a bias towards facts, emotion, evidence-base data, access and creating a sense of urgency/call for action.

What are must-have tools for advocacy?

Although the tools will be different depending on the objectives, in most cases an advocacy campaign will involve the following tools:

- Website with advocacy information including:
  - patient testimonials,
  - fact sheets and reports,
  - sample letter to health policy-makers,
  - sample letter or opinion piece for the media,
  - call to action to committed patient advocates

This information can be adapted to be used on other social media interfaces such as Facebook, Twitter, YouTube.

- Position papers on key issues
- One key event around an important milestone with a press release to explain/support the context for the event.

What kind of event to choose from?

There are different kinds of events:

- ***Content events:*** conferences, seminars or workshops where you invite an academic, politicians and/or government officials to speak or participate in a discussion on a particular topic. While increasing the value of your own event, you would also be providing your target audience with a platform to profile themselves.
- ***Event co-hosted with another organisation:*** There may be the opportunity to co-organise events with other establishments such as other patient organisations, reputable universities, research institutes or think tanks, where there is a common interest or where the organisation in question has worked with you on a piece of research. This type of collaboration lends further credibility to your initiative and creates an opportunity to invite a politician to speak at the event.
- ***Parliamentary events:*** Organising a parliamentary event enables you to reach out to more than one Member of Parliament (MP) at a time. The fact that any event organised in the premises of a national Parliament needs to be officially hosted by an MP provides a special relationship-building opportunity. Although the MP is generally doing the organisers a favour by accepting to host the event, it also provides them with the opportunity to increase their profile with colleagues who share political interests.

Organising or sponsoring an event, workshop or debate could involve different degrees of engagement.

- What issue do you want to focus on?
- Is the event part of a larger strategy that will help meet your overall objectives?
- What is the best timing for the event?
- Who is your target audience?
- What are your key messages?
- What is your ideal outcome?
- How will you follow-up after the event?

What are position papers?

Providing health policy-makers and third parties with position papers and personalised briefings allows you to further explain your position and include key facts and case studies. This is an important tool as it allows you to state your organisation's position regarding a certain issue that affects people with gynaecology cancer, and communicates your message in print, thereby strengthening your advocacy campaign. It can be 'left behind' in a meeting or shared with your audience at an event you organise. It's also worth considering having as many supporting entities as possible to sign off on your position paper including medical/scientific institutions.

- ***Site visits:*** a visit to a multi-disciplinary treatment centre in gynaecological cancer organised with a hospital, led by a clinical nurse specialist for an MP who sits on a committee with the power to influence budgets, or for an expert involved in setting national guidance can be very effective – why not combine it with some media coverage too.

Making sure personal meetings with health policy makers are a success

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

1. Target the people who matter. Your political stakeholder mapping (STEP 3) should identify a core group of 10 to 15 of your targets.
2. Respect the decision-making process. Lower-level officials draft legislation so contact them first. However, approaching higher political levels will be more beneficial if there is a lack of interest in your issues, negotiation deadlocks or high political stakes.
3. Ensure your representative is comparable to your official in terms of seniority and influence.
4. Do your homework on the official. Find out what they might expect from a meeting.
5. Ensure that you meet expectations. Give information, suggest health policy change and offer networking advantages.
6. Arrange the meeting at the right time in the health policy and/or regulatory procedure.
7. Maintain contact even when you do not need help.
8. Offer your assistance even when no critical issue is at stake.
9. Always leave something behind (executive summary, position paper or 'gimmick') to remind them of your visit and your key messages.
10. Follow up with a 'thank you' letter and send any extra information that may be useful and relevant.

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

An initial introductory meeting to exchange views is beneficial for both parties. This allows you to learn what they are focusing on and to adapt your input and messages accordingly. However, there still needs to be a good reason for arranging a personal meeting with a health policy-maker as they usually have tight agendas. A meeting for a meeting's sake is not advisable. Personal meetings should be reserved for times when an issue is being focused on, even if it is in an early stage.

How much do tools cost?

Limiting factors for many tools is are the costs and resources that need to be dedicated to them to create them. Please see STEP 8 on budget and resources reality check.

STEP 7 - Developing your action plan

> "People don't plan to fail; they fail to plan."
>
> John L. Beckley

Turning dreams into reality

By now you have gone through a very important exercise of developing your strategy. You know what you are trying to achieve (STEP 2), who your targets and potential partners are (STEP 3) and how you are going to deploy your resources (STEP 5), and what tools are potentially the most appropriate for you (STEP 6). Now it's time to think how you will turn your strategy into reality. An advocacy action plan will help you make sure that your organisation has a concrete roadmap to achieve the objectives you set.

The Action Plan will guide your day-to-day efforts to implement the strategy and will provide a complete overview of:

A. Activities chosen to reach your objectives

Decide which advocacy methods should be used (please check STEP 6 for possible advocacy methods and tools) based on the following criteria:

- Will the chosen activities resonate with our target groups?
- Do we have enough resources (human & financial) to develop/implement them?
- Do we need any external support e.g. from partners? Can we leverage something that another ENGAGe member has done?
- Are they time sensitive?

You might also want to check what is being done at the European level and how it can be tied up with your Action Plan. Maybe there are some ready-made tools and activities that you can use after adapting to your national circumstances?

B. Specific time when you want implement the activities

While choosing your activities, you need to think about when could be the best time to implement. Answering the following questions might help you do this:

- What are the **external milestones** we should take into consideration? These might be e.g. legislative deadlines but also other milestones which give you an opportunity to push your message out (see the box for some examples). You might also want to take into consideration a broad political picture e.g. during election times politicians may or may not be more willing to make bold statements;
- What are the **internal milestones** that are important? For example, if you are planning to conduct a "train the trainers" session for your patient advocates, you might want to do this at the occasion of another meeting, which is already taking place to save time and financial resources.

Thinking strategically is very important at this planning stage. Advocacy activities can often have a greater impact if they are timed to coincide with other actions or events that will help your advocacy work.

C. Division of responsibilities for implementing the activities

It is important to clearly state **who** is responsible for implementing each activity and **when** they should do this. If you are working with a coalition partner it is also necessary to include the division of tasks between both organisations and define the coordination mechanisms.

D. Resources needed to implement each step of the action plan

Finally your action plan should also include information about human and financial resources needed to complete each task. While you might have already looked at each activity separately, it is also very important to put all this information together to have an overview of the overall workload and financial input needed. This might lead you to scaling up or down your action plan to resources available or indeed to look for more cost-effective solutions (please see STEP 8 for Resource Reality Check).

When you complete the exercise review the action plan once again and make sure that it reflects your strategy. It should also be:

- **Complete** - does it reflect your objectives and allow you to reach all your target groups?
- **Clear** – is it apparent who will do what and by when?
- **Up-to-date** – does it reflect the current work, does it anticipate upcoming opportunities?

It's a living document

Your Action Plan should be a living document guiding your everyday work to help you achieve your objectives. Don't put it in the drawer but consult frequently to see if your team is on the right track. Keep track of what and how well was done. New things will happen, which can either be opportunities such as heightened interest in an issue, for example Angelina Jolie and cancer; other developments may require you to delay or remove elements of your action plan, for example elections or budget reallocation. If external or internal circumstances change your action plan should also reflect those developments.

Celebrate along the way

Advocacy planning is generally something to engage with over the long term. Nevertheless, your Action Plan can help you and others who are helping you stay motivated. Each completed activity is a small success on your long road to accomplishing your mission, so don't forget to celebrate along the way!

An external milestone for you?

- **International Days**
  - **Disease related** (e.g. World Cancer Day – 4 February; International Gymea Awareness Day – 10 September, World Ovarian Cancer Day - May 8, Rare Disease Day 28 February)
  - **Non-disease related** (e.g. International Women's Day – 8 March; Mother's Day – date differs depending on the country)
- **Major events and conferences** organised by other NGOs, government, third-parties or your partners
- **Political calendar (elections)**

STEP 8 - Budgeting and resources reality check

Too little time, not enough money?

The greatest plans often fall by the wayside because not enough care goes into making sure they are feasible. Success comes down to careful planning, some material resources (cash, time and people), a bit of nerve and a lot of persistence. The resources needed to carry out an advocacy plan revolve around having enough:

- committed patients and their availability to engage
- expertise to carry out specific tasks identified in the plan (for example social media skills or writing a position paper, translating important research)
- and then there's the challenge of having enough money whether it's to cover travel costs, room hire and catering for an event, or funding research or covering printing costs. In addition, when you cannot find the expertise/skills for specific tasks, you may also need budget for that (e.g. a web-designer for your website).

What resources will you need for an advocacy plan?

There is no magic number or formula to say that you have or don't have enough resources to implement an advocacy plan. The only way to work that out is to take the action plan and review the description of the different activities you plan to carry out and against each one, identify the resources you will need to make them happen. Ask yourself:

- Who are the key people you will need to have involved to carry off the activity? You should be clear of what you will be asking them to help with and how much of their time you think it will take.
- How labour-intensive will it be for the patient organisation? Try to identify who will provide the labour and over how long?
- What skills are needed and how much will these skills be called upon? This is a very important area and you skip it at your peril. List the skills you might need: expert writing (position papers, patient testimonials, summaries of research, press releases), design/layout, IT, medical, academic, translation or interpretation.
- What activities are on your plan that you will need cash or "in-kind" support? And how much? As we all know from personal experience, the easiest thing to fall out about is money – either taking it for granted that somebody will pay something (e.g. travel to a meeting), or receiving money and not using it efficiently.

Think smart about resources

The exercise is an iterative process and you may find there is overlap between the resources you need for one activity or another. To rationalise resources, you may go back to your strategy or plan and rethink things to leverage or save on resources. We often do it intuitively, for example if you have an annual meeting when many of your key supporters and experts gather, to save on travel costs and time you might add onto the annual meeting a series of meetings with health policy makers.

The acid test – ask yourself:

Is the investment of time, resources and people worthwhile in terms of improving the lives of women with gynaecological cancer, their close ones and women who may be at risk?

Leverage or save resources:

- Refine the target audience - Activities involving the "general public" may not be a wise use of resources. The 'public' consists of numerous diverse groups of people and individuals with different interests and motivations. It is unlikely that any campaign will capture everyone and it is even questionable whether it would make much difference if it did (since sheer numbers do not equate with campaign success). This blanket approach is also wasteful of scarce resources. Go back to STEP 3
- Find where the information may already exist:
  - Remember that pharmaceutical industry companies spend a lot of time and resources looking for evidence to support their own therapeutic areas of interest. By developing positive relationships with these companies you could be able to tap into their resources. They may be able to provide off-prints of research that could be useful for health policy-makers, as well as translations.

– ENGAGe network may already have done something similar, for example advocacy tool kits, position papers, event programmes.
– Other cancer patient networks may also be able to provide materials.

Secure resources for essential parts of the plan

Even when you have done your best to think smart about the resources, the question will arise as to where you can find the resources, especially cash. This is a key reality check moment. If the resources you need are so completely over and above anything you could envisage, then you may be advised to go back to the beginning and trim back/prioritise your work. You could think of "must do" activities without which your plan has no chance of succeeding, and "nice to haves" where you can reach out to people to try to secure their support and cash, but if the resources are not forthcoming, then you will not go ahead with that activity.

Everything has a price and you should know it

You may find that you have a good idea of people, expertise and time needed to do something, the area that many people feel less confident about is estimating the cost of things. Once you have identified activities, which will have costs related to them, you can start to explore how you can best cover the costs or whose help you could call upon to cover the costs. So even if you might find a solution for somebody else to step up and cover the costs, it is still necessary to have an idea of what it represent in monetary terms. Don't forget that you are competing for resources with many other organisations, and you'll have to make the case in a way that shows you understand the value of the support you are seeking as well as being able to demonstrate the impact that it will make. Finally, organisations, government bodies, universities all have budget planning cycles – and it is advisable to understand these so that you can come forward with your proposals before budgets have been fully allocated.

Things you may be able to obtain from pharmaceutical companies (or other companies):

The general benefits of working with industry include:

- securing funding
- access to other resources, e.g. IT equipment, literature, fundraising events, printing services
- skills sharing.

In addition to securing funding, resources and skills sharing, other benefits of working with pharmaceutical/healthcare industry partners include:

- access to information, educational materials, scientific data and equipment
- knowledge of country-specific markets and barriers to treatment access
- better and more timely understanding of regulatory and safety issues about specific drugs
- information about pipeline products and planned and on-going clinical trials
- access to networks of contacts, including access to key opinion leaders
- informal pharmaceutical/healthcare industry advice or opinion
- an additional voice for advocating health policy makers
- opportunities to attend conferences, workshops and other professional development events
- greater understanding of options for managing health conditions.

Review resources as you go along and at the end

Organisations that provide funds to support patient groups are interested of course in a successful outcome, but they are also want to be reassured that financial situation is being well managed and that budgeting is effective. For this reason, regular meetings and/or reports are necessary to demonstrate that the activity is progressing as planned, is on time and on budget. Flagging up at any point if an over-run of budget or timeline may occur, at which stage you may have to agree a new timeline and budget, or stop the project.

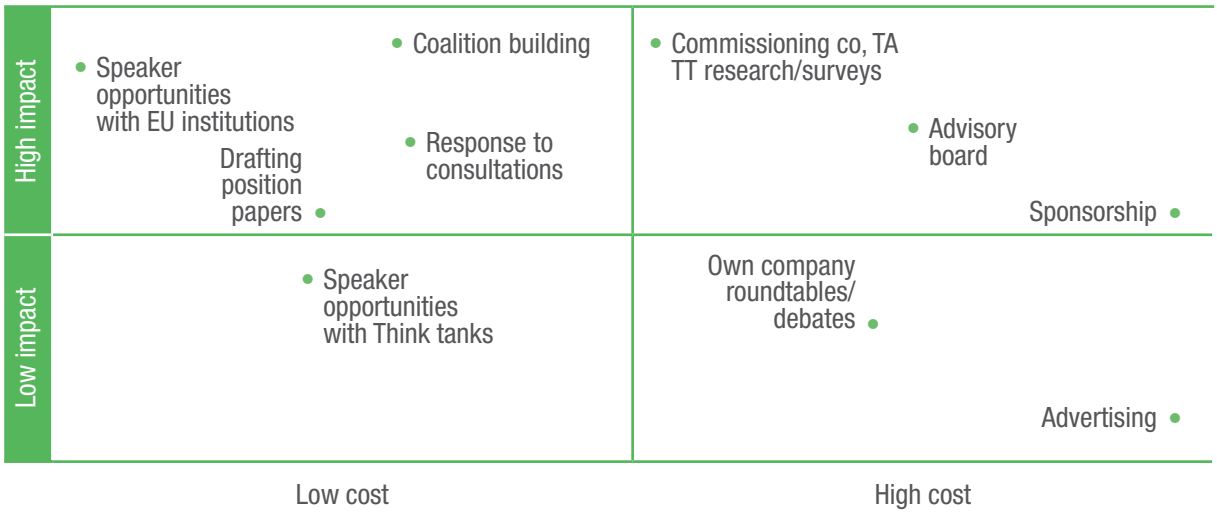
At the end of a project where organisations have been involved and have supported your activities, it would be advisable to review it based on:

- Whether objectives were achieved on time and on budget
- Benefit to patients
- Benefit to your patient organisation
- Identify key learnings from the project.

Try to plot your advocacy activities on an impact vs cost chart

Referring to your action plan, you can map out the activities in an impact vs. cost chart. Activities are plotted on the chart. In the "High impact/low cost" quadrant, you will then identify the activities that are most attractive from a resource perspective whereas the 'Low impact, high cost' will be less compelling. Plotting activities in this fashion will provide you with a useful basis of discussion and ensures that you are able to articulate the benefits and impact of an activity in relation to its cost.

IMPACT VS COST CHART



STEP 9 - Engaging and maintaining relationships

When looking at your key audiences and doing the research to understand their interests and influence (STEP 3), you should have drawn up a list of the most relevant people to reach out to for your advocacy plan. Top of the list will have been political decision-makers and health policy-makers more generally. Once you have identified the most important (top 10 to 20 people), and you know what you want to say, have prepared the tools to back it up, you will be ready to engage with them. This is not a one off activity, it's a process which needs to be researched, prepared and managed over time in order to achieve the desired results.

How to influence health policy makers?

One of the most effective ways to influence policy is to create champions amongst the elected representatives in the parliaments and other governing bodies in the country in which you work. However, a champion is not someone who merely votes the right way or supports a bill/policy your organisation supports. A champion is a member of Parliament or Congress (or whatever the elected body in your country is called) who takes on the issue as a priority and does their utmost to make sure change happens. Other health policy champions taking decisions which relate to your advocacy plan may sit on government or professional organisations.

Key steps in working with political decision-makers and health policy-makers more generally:

1. Identification: Who do you need to influence? What do they know already? What else do they need to know? See STEPS 1, 2 AND 3 of this guide
2. Engagement: Reaching out and building a relationship/partnership.

- Education: What do they need to know, see and hear? How can I best do this? Who can I introduce them to?
- Motivation: What will motivate them into action? What is in it for them? Why would they care? What can I show them that will make a real difference?
- Action: What specific actions do I want them to take? Who else can they work with on it?

Once engaged, always engaged!

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

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

Make sure you track your activities so you remember who you saw when and received what.

Health policy makers believe the media is important – so should you

The media can play a crucial role in getting your message across to carers, the general public and your targets. Remember, politicians read newspapers as well.

The media will be vital for raising the profile of your organisation and for achieving the attention of health policy-makers, government officials and other third parties. It is a very important industry as it holds a powerful sway over national governments. It can also influence the electorate, report on government affairs and is interested in political decisions and policy objectives. In order to catch the interest of both the policymaker and the press, it is necessary to build a relationship with your national and/or regional media.

National newspapers and specialised healthcare media are all key targets for media outreach. Their publications will be read not only by women with gynaecological cancers but also carers, innovative leaders and healthcare professionals as well as women in general for whom prevention and screening information is essential. Academic publications as well as publications

for health professionals are also important – and increasingly offer opportunities for patient advocacy. For the example, The Lancet uses its editorials to influence decision-makers – not only the medical / scientific community but also general media that pick up and use the Lancet as a reference.

In addition, social networks sites focused on women (e.g. Mumsnet www.mumsnet.com) as well as lifestyle reporters/publications who may be interested in "human interest" stories are influential for advocacy campaigns. Demonstrating your issues through personal stories may get more mainstream reporters' interest.

Using third parties to lend their weight to your position

In addition to the media, other groups are influential with health policy makers and can help your cause – these are called third party advocates.

Natural third party advocates include gynaecological oncology specialists, doctors, academics and university professors with expertise in oncology, health workers involved in treatment plans, screening and prevention in your advocacy plans. In addition, consider linking with umbrella patient organisations that advocate for patient rights and/or women's rights. Although these groups cannot make national decisions, they can be highly effective in building a strong campaign and influencing policymakers.

Who else influences political decision-makers?

Health policy decision-makers get their information to make decisions from a variety of sources: colleagues, staff members, constituents, media, experts, and by their own experiences. These sources help health policy-makers identify cases that support their agenda, as well as assess how much support they may get for a stance they might take. Patient groups can have a powerful voice but you will need others to reinforce your messages. Reaching out to other influencers, and building relationships with them, will be crucial to the success of your advocacy campaign.

Third parties can lend their weight to your advocacy plan in any number of ways. The trick is to have done sufficient research to know what is a realistic "ask". They are influential as they can be seen to be speaking at political conferences, attending public hearings and adding to national debates. Unlike policymakers, academics and medical experts are more accessible for national voluntary organisations to arrange meetings with and they can often have more empathy for your cause.

You can engage with them in many ways. The most influential third party individuals or groups should be engaged in just as rigorous a fashion as that described for health policy-makers.

Build up your media list

Build up the list over time.

1. Use online search engines such as Google News to manually identify national and regional media contact information.
2. Twitter "followers" provides a good insight to the types of media that health policy makers who are active in social media consult.
3. Put on your list: name of the publication, name and surname of the journalist, their title, email, telephone number and twitter handle.

Don't be too ambitious, better a few good contacts that you really know and understand what they are interested in, than a long meaningless list.

As other cancer patient groups if they have a list you can start with and they may have advice on how to engage with the media

STEP 10 - Monitoring and measuring success

Learning by doing

As with any long journey, progress needs to be checked along the way. Monitoring and evaluating the effect of your activities is extremely important as it helps you measure their impact and improve the outcome of work along the way. There is nothing scary about the process – remember that by doing it you are also learning as you go along how to adapt your strategy and advocacy action plan. It will also help you demonstrate to potential donors/sponsors that your efforts are delivering desired results.

Monitoring comes first

Advocacy success comes in many forms, it can be a great event where you filled the room, it can be when you get the support of a politician to support research funding in your area. Evaluating advocacy efforts can sometimes prove challenging, as it is difficult to know precisely what has contributed to policy change. Some other organisations may be working to achieve similar aims or objectives via different means, so it is hard to determine the impact that your work has had. However, this should not discourage you.

What you need to remember is to "build in" monitoring and evaluation into your advocacy effort at the outset, ideally while the strategy and action plan are being developed or soon after.

What to measure? Activity or impact?

Whatever you measure has to relate to your objectives; whether you are measuring outputs (activity) or impact. Measuring outputs or activity e.g. how many meetings you hold, or how many people attend an event, or how many views of a post on Facebook or other social media channel can all be valid measurements, especially if they relate clearly to a strategy. For example, how many meetings you have in a year can be relevant if you tie that into a meetings programme strategy and you have a list of 10 to 20 identified key decision-makers to have face-to face time with. In which case, measuring in Year One that you had meetings with 50% of your targets can be useful to note – and you can ask yourself is that good enough? If not, how can you rethink your approach to get closer to 80 or 90% the following year? That's when measuring output becomes useful – as it can help you ask the questions, with a degree of objectivity.

Measuring impact is about seeing to what degree you have "moved the needle": Did you "increase awareness" of gynaecological cancer among policy makers? Did you "increase opportunities for patient involvement in research"? To be able to do that, you will have to make sure you have a clear overview of where you start and then the necessary systems in place to monitor progress so that you can then measure how far you've come.

Sample areas of measurement:

- **Process related** – demonstrating the effectiveness of your activities
- **Stakeholder outreach related** – demonstrating impact on targets
- **Satisfaction or reputation** - stakeholder awareness/ favourability related (could also have an internal satisfaction dimension)
- **Policy related** – demonstrating impact on policy

Start with defining where you are and where you want to be

Before starting to implement your strategy and action plan think where you are at the moment and where you want to be in the future. Monitoring and evaluation will be much easier if you develop a clear aim and objectives and desired outcomes in STEPS 2 and 7, stating clearly what you are trying to achieve. Below you will find a couple of examples of how to quantify your goals for measurement:

Non-measurable goal	Measurable goal
Seek awareness improvement of gynaecological cancer patient care	seek ....% awareness improvement of gynaecological cancer patient care among **chosen stakeholder group**
Reach out to many policy makers during the campaign	Reach out to **80** policy makers **active around your issue** in the first year of the campaign
Advocate changes in the guidelines related to gynaecological cancer patient care	Ensure **introduction of XXX amendments** to current guidelines related to gynaecological cancer patient care

Keep an eye on the progress

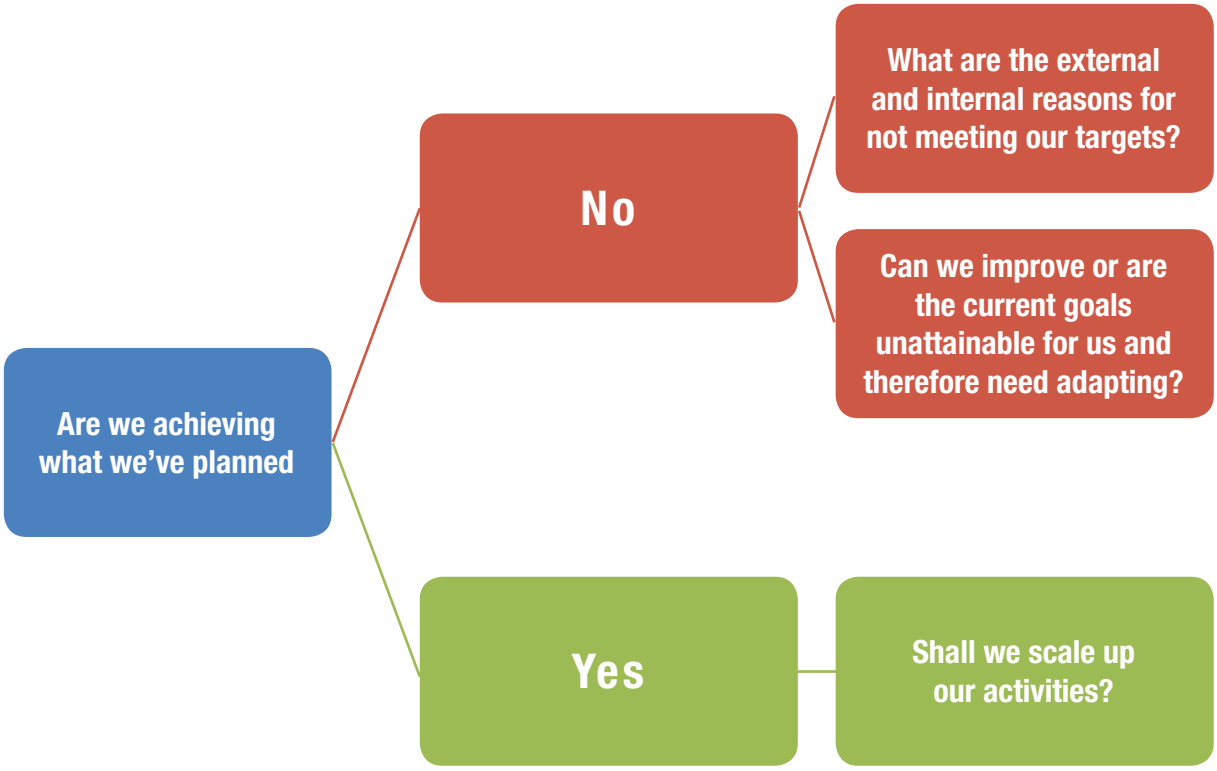
Monitor the progress along the way while looking at your activities and changing environment by:

- Observing chages in the rhetoric and actions of your target audience (e.g. through monitoring media, speeches, official documents).
- Monitoring changes to guidelines and policies (if relevant) e.g. guidelines for gynaecological patient care
- Collecting hard data and facts related to delivery of planned activities (e.g. the number of meetings, events, number of people trained, etc.)

You might also want to use some useful tools to monitor the effects of your work e.g. small-scale telephone polling with your key stakeholders, focus groups, online survey (e.g. Survey Monkey which is easy to set up and allows you to understand how people are reacting to your campaign).

Evaluating the results

Once you collect your monitoring result it's time to compare them with your strategic objectives and draw some conclusions for future work. You might want to answer the following questions:



Keep the good work going

Monitoring and evaluating your activities is very important. However, it is equally crucial to maintain your efforts and do not get discouraged even if things do not go as you had initially planned. A good campaigner does not give up and believes that their efforts will pay off in the longer run. Public policies rarely change overnight but by being patient and persistent you can make it happen.

Notes

Notes

ENGAGe

ESGO European Network of Gynaecological Cancer Advocacy Groups

About ENGAGe

What is ENGAGe?

Established in 2012, the European Network of Gynaecological Cancer Advocacy Groups is a network of European patient advocacy groups established by ESGO representing all gynaecological cancers particularly (ovary, endometrial, cervix, vulva and rare cancers).

Why is ENGAGe needed?

- There are wide variations in patient care across Europe. Patients are not adequately informed about gynaecological cancer and their management.
- Survivorship issues are not adequately addressed and psychosocial support in general is poor.

The ENGAGe objectives are to:

- Facilitate the development of national gynaecological cancer patient groups in Europe and to facilitate networking and collaboration between them.
- Disseminate information and share best practices to empower patient groups and improve the quality of care across Europe.
- To increase patient representation in ESGO activities by education on current research and health policy.
- To advocate patient care policies practices and access to appropriate care at both national and European levels.
- To educate patient groups, health professionals, the public and health decision makers.

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