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ADVOCACY:

A Guide for Patient Advocacy Groups

EM-104199

Advocacy: A Guide for Patient Advocacy Groups©

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Disclaimer: The views expressed in this publication are the authors' and do not necessarily represent those of the American University of Beirut.

ACKNOWLEDGMENTS

We would like to extend our gratitude to the representatives of the Patient Advocacy Groups (PAGs) from Egypt, Lebanon, South Africa, and United Arab Emirates for the time they allocated during the consultation meetings that took place in 2021, which led to the development of this guide. Their input was instrumental to ensure it was developed in an inclusive and participatory manner.

Special thanks goes to Dr. Rita Karam and Dr. Mirna Matni for their dedication and patience in writing the guide as well as to Mr. Ahmad Nofal for developing its Arabic version. Lastly, I wish to extend my special regards to Ms. Amani Jamal for making the guide a reality in the first place.

Joumana Kalot, MPH
Activity Director

This guide was produced with the support of Janssen Emerging Markets EMEA

FOREWARD

This guide is designed for use by patient advocates as material for conducting capacity building in advocacy. It takes tremendous effort to be a reference for patient advocacy groups (PAGs) and Patient Communities.

This reference guide provides the needed material for advocacy of preserving patients' human dignity, promoting patient equality, and providing patients' freedom from suffering. The guide also highlights patients' rights to make decisions about their own health.

Rather than a homogeneous field, patient advocacy is driven by the needs of the respective patient community and can for this reason span domains as diverse as communications, investment strategies, and law.

The added value of this guide is its creation by experts in patient empowerment through advocacy to help improve people's lives, family dynamics, group processes, organizational functioning, and community-based services. Keeping in mind this patient- centered approach, the guide covers three important areas in which education, empowerment, and advocacy can improve the information, knowledge, and skills of PAGs and patients. The three main topics developed in this guide include Advocacy Essentials, Patient Advocacy Strategy, and Communication in Advocacy. The guide also offers easy and simple advocacy tools, templates, and real examples in the form of case studies. Note that the Policy Advocacy is not within the scope of this guide.

The aim of this advocacy guide is to develop a living resource that grows with the needs and interests of the PAGs and patient's community and that incorporates professional-grade insights, tools, and methods in the areas of communication, management, and strategy, together with suitable "how-to" introductions and templates.

We hope this guide will contribute to a better sense of understanding of what advocacy is and how it can be used to enhance patient advocacy capabilities while empowering strategic thinking and implementation alongside effective communication ability.

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INTRODUCTION TO THE GUIDE

The guide contains four modules that lead users through various steps in Advocacy.

- Advocacy Essentials
- Patients Advocacy Strategy
- Building the Foundations for a Successful Strategy in a Nutshell
- Communication in Advocacy

WHO SHOULD USE THIS ADVOCACY GUIDE?

This guide is for anyone who wants to make a difference in the field of study of a specific disease. It also functions as a roadmap to prepare the reader with the information required to effectively carry out the role of patient advocate
This guide is aimed at both new and experienced advocates. Its purpose is to help the reader get acquainted with patient advocacy, to serve as a repository to go back to, and strives to provide new material even for experienced advocates

WHAT DO WE HOPE THIS GUIDE WILL ACHIEVE?

Many patients have no time to lose, and successful advocacy draws on expertise from many different fields. Given the right tools, anyone can progress faster – and make a difference to patients by stimulating collaboration and partnerships to strengthen the collective voice as well as advocacy initiatives, which will bring about progress and change.

HOW TO USE THIS GUIDE?

This guide can be used as a template by advocates to identify their goals, create a strategy and define key messages, identify co-partners, and allocate time effectively.
Depending on the level of advocacy, the guide can be adapted to an advocate's practice or work environment. It provides many practical and workable suggestions for developing short and long-term activities to advocacy.

1. ADVOCACY ESSENTIALS

1.1. WHAT IS ADVOCACY?

The World Health Organization (WHO, 1995) describes advocacy for health as a "combination of individual and social actions designed to gain political commitment, policy support, social acceptance and systems support for a particular health goal or programme." Patient advocacy gives a voice to a spectrum of healthcare stakeholders including patients, survivors of an illness, and caregivers.
An advocate can take more than one form, including an individual, organization, or both. The target of an advocate's activity concerns a certain disorder or group of disorders including either, all, or part of the patient community. Patient advocates rely on meaningful relationships with their patients to ensure that they can meet all their logistical and healthcare needs. However, patients are facing even more challenges in their advocacy activities due to the surge in disease incidence rate.

A wide-ranging number of activities fall under the definition of patient advocacy. These include but are not limited to the following:

- Patient representation
- Ensuring patient rights
- Education of patients and their families on the disease and its comorbidities
- Education of patients' healthcare providers on disease management
- Continuous support and information on financial, scientific, or social support with all types of information needed on disease management, reimbursement, policies…
- Collaboration and sharing between different stakeholders
- Building awareness around the disease
- Advocating for healthcare access
- Advocating for medicine and technology availability and accessibility

Advocates represent PAGs on a wide platform to effectively raise patient issues. Patient advocates might liaise with political bodies and healthcare entities, inform the public, and work with healthcare professionals, academia, and medical and pharmaceutical research communities.

Their role is wide-reaching and encompasses many areas. It acts as the connecting link between groups of diseases, healthcare professionals, patients and survivors, medical researchers, and political legislators.

The following case study illustrates a case on the role of an advocate:
The role of an advocate is to represent patients and patient groups on a wider platform to effectively raise awareness of the issues they are facing. In this case, patient advocacy's role in supporting, connecting, defending, and showing evidence assisted the patient in obtaining her right to proper medical care and overcoming the obstacles by seeking the related law.

A CASE STUDY ON PATIENT ADVOCACY/ PATIENT LEGAL SUPPORT

CASE STUDY

A pregnant woman arrived at the emergency department with a male partner. It appeared as though she was in active labor because the woman kept walking back and forth, demonstrating excruciating pain. A guard on duty directed the male partner to an attendant to register the woman as a patient. The attendant requested valid identification along with a social security number and health insurance information before beginning the process.

The ethical and legal contentions of this situation were rooted in that neither the woman nor her partner possessed any valid identification, social security numbers, or health insurance. They both claimed to be undocumented and could not obtain state identification, social security numbers, nor afford health insurance even though they had been in the country for more than twelve years. Meanwhile, the booking attendant reacted negatively as if this case was an anomaly in the institution.

While the pregnant woman waited and the pain intensified, the attendant continued arguing with the couple to the point of humiliation; the incident was brought to the emergency department nursing manager who is a well-known patient advocate. Quickly, he called the attendant aside and informed him of the emergency medical and active labor act which became law in 1982. The law clearly states that “hospitals provide care to anyone needing emergency treatment regardless of citizenship, legal status or ability to pay” (Zibulewsky, 2001, p. 339). Immediately, he directed the clients to another booking attendant after apologizing for the misunderstanding.

CONCLUSION

Potential barriers to advocacy in this situation could have been a feeling of powerlessness. However, this was mitigated by the presence of the emergency department nursing manager known to be a patient advocate. The next barrier might have been a lack of advocacy support. In this case, the emergency medical and active labor act was the legal means available to overcome or to solve the problem

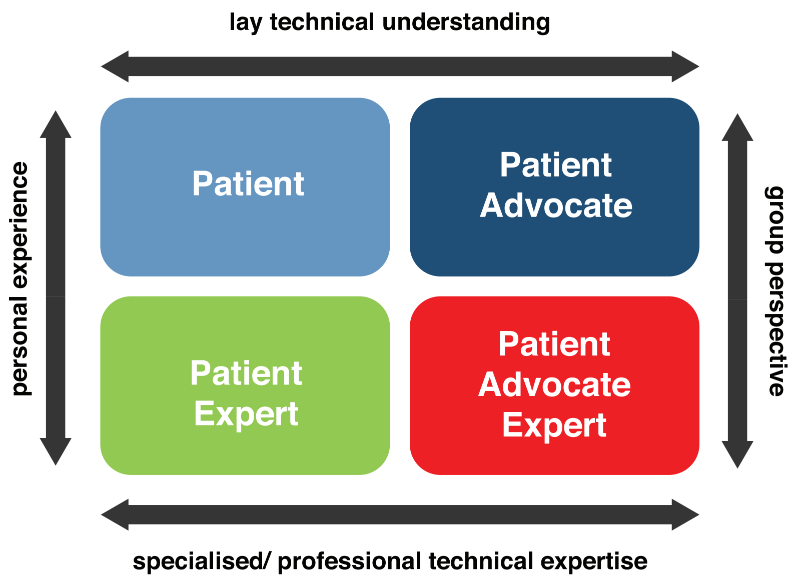
1.2. WHO IS A PATIENT ADVOCATE?

Whether paid or volunteer, many people choose to act as patient advocates and assume a range of roles including but not limited to: listen to patient concerns, respond to a complaint, explain hospital policies and procedures, assist patients in finding community services, provide information on payment coverage or discuss a concern between the patient and his medical team
Their goal is to support their own communities, promote campaigns, and advocate for the patient's interest and rights. An advocate will need to work on different levels of service with different types of people as a focal point for the patient community and medical bodies.

While a medical background is not necessary, a patient advocate will usually partake in intensive and specific educational programs and trainings. An advocate needs to be chosen with care to make sure that he/she has the necessary qualifications to fulfil her/his role in a professional and balanced way. An advocate must be trustworthy and is entitled to act in the interests of those she/he represents as she/he should be accessible to the wider community. Ultimately, an effective advocate is **a person who is knowledgeable of the role and the conditions of the represented group. This can include family members, close friends, or acquaintances.**

Patient involvement - input = output.

Patients, patient advocates and levels of expertise



Patient
concerned with own condition

"Patient expert"
Patient with specific high-level expertise

Patient advocate
concerned about the group of people with condition

Patient advocacy expert
Patient advocate with specific high-level expertise

A patient group or organization will be formed by patients, patient experts, patient advocates, and patient advocate experts. The structure of the organization highly depends on the interest and expertise of every individual involved in the advocacy process.

The following case study illustrates the level of expertise of a patient advocate. Janice was knowledgeable, well-trained and able to identify problems Anna was facing. She didn't only provide her with all the necessary guidance and assistance, but she also helped the patient to self-advocate and partake in the decision-making process.

CASE STUDY

Anna is a 50-year-old female with a new diagnosis of rectal cancer. She does not have any type of health insurance and is living temporarily with a friend. The colorectal nurse from the National Oncology PAGs, Janice, arranges for Anna to be seen in the multidisciplinary colorectal clinic where she meets with a surgeon, medical oncologist, radiation oncologist, nurse navigator, and social worker. The team recommends chemotherapy and radiation to begin in one week.

At the conclusion of the clinic visit, Anna meets with Janice to discuss next steps and address barriers to care. Anna tearfully tells Janice that filling out the financial paperwork is too overwhelming and asks her to complete the financial assistance application, help her apply for disability, and find her somewhere to live during her treatment course.

Janice understands that a significant role of the nurse from the national oncology PAGs is to empower patients by doing with them, not doing for them. She also recognizes that Anna is overwhelmed and needs time to process this life-changing diagnosis and treatment course.

Janice assures Anna that the oncology team can help and asks her what she feels is the most important step toward completing the requested tasks. Anna is unsure, but says her friend told her she could continue to stay with her during treatment, so that is not the biggest problem. Janice suggests a meeting with the financial assistance counselor the following day and tells Anna what documents she will need to bring with her (bank statements, income tax records, etc).

Janice helps Anna break down a sizable task (applying for financial assistance) into a small assignment (gathering her records). This strategy empowered Anna as she succeeded in completing the financial application; one step at a time. Over the course of the next few weeks, Anna completed her application for financial assistance and started treatment. The social worker also helped Anna with decisions about employment and disability.

CONCLUSION

Oncology PAGs promote patient empowerment by identifying problems and resources to help patients solve their issues, self-advocate, and partake in the decision-making process throughout their care.

Patients by ensuring they know their options and identifying their preferences and priorities; providing patients with strategies to cope with their disease, treatment, and stress; and assisting them to access healthcare services. PAGs have the unique opportunity to lead patients to achieve their goals by assisting them in identifying sources of empowerment within their personal health situation, encouraging participation in their care, and focusing on patients' self-determined needs.

1.3. WHY AND WHEN TO ADVOCATE?

Most patient groups advocate individually by “asking” for minor changes in their daily lives (more accessible bathrooms, flexible working conditions to accommodate chronic conditions or care for another patient). However, for a wider reach and representation, a person or group that has the capacity to invest more time and energy in advocacy is required. This is where patient advocates come in.

An advocate’s role is to step in and mediate to move things along for the best outcome for all those concerned. This can range from something as simple as pressing for a local community service to advocating on an international level for pharmaceutical access.

There is no ideal time to advocate; rather, advocates are constantly active and are working behind the scenes to ensure that the groups being represented remain at the forefront of the discussion that concerns them. In this way, advocates support the community they are advocating with the vital service in reassuring marginalized groups that their concerns, including the issues impacting their lives, are being brought to the table for discussion.

Patient advocates can provide services and education for the community members to reach the most favorable outcome. Independently at any time, the following case study illustrates how Mr. X, a patient advocate, provided both education and services to male patients.

The aim was to counteract false information and rumors that are spread in the community, and to help in the identification of sick people to provide them with healthcare services later.

A CASE STUDY ON PATIENT ADVOCACY / COMMUNITY OUTREACH ADVOCACY

The **Tanzania 50 Plus campaign – Tanzania** scheme focuses on education, advocacy, and support for prostate cancer patients.

Rev. Canon Dr. Emmanuel Kandusi, a prostate cancer survivor and the founder of the Tanzania 50 Plus campaign, believes in the need for community outreach advocacy in prostate cancer. Grassroots programs such as this one are directly targeted at the needs and interests of the audience.

The first activity of the outreach program provides information about prostate cancer and works to counteract false information or rumors in the community. This education program can occur in a variety of settings, including places of worship, to spread information to the largest audience possible.

Second, it provides informed voluntary free prostate-specific antigen tests called "harbinger," body mass index tests, and body fat tests.

Third, from experience they identified that many sick men are unable to reach medical services. Therefore, the organization runs an ambulance service to transport elderly people to and from hospital.

For those unable to leave home, support visits are undertaken to counsel terminally ill patients, and in some cases to subsidize medical costs.

1.4. WHERE TO ADVOCATE?

Advocacy takes place in any place at any time, whether inside homes, on large conference stages, in person, or otherwise. The organic nature of advocacy represents a service which grows within communities, from person to person and from group to group. Advocates often exchange information and knowledge to help each other represent the groups they serve.

2. PATIENT ADVOCACY STRATEGY

2.1. BUILD A STRATEGY

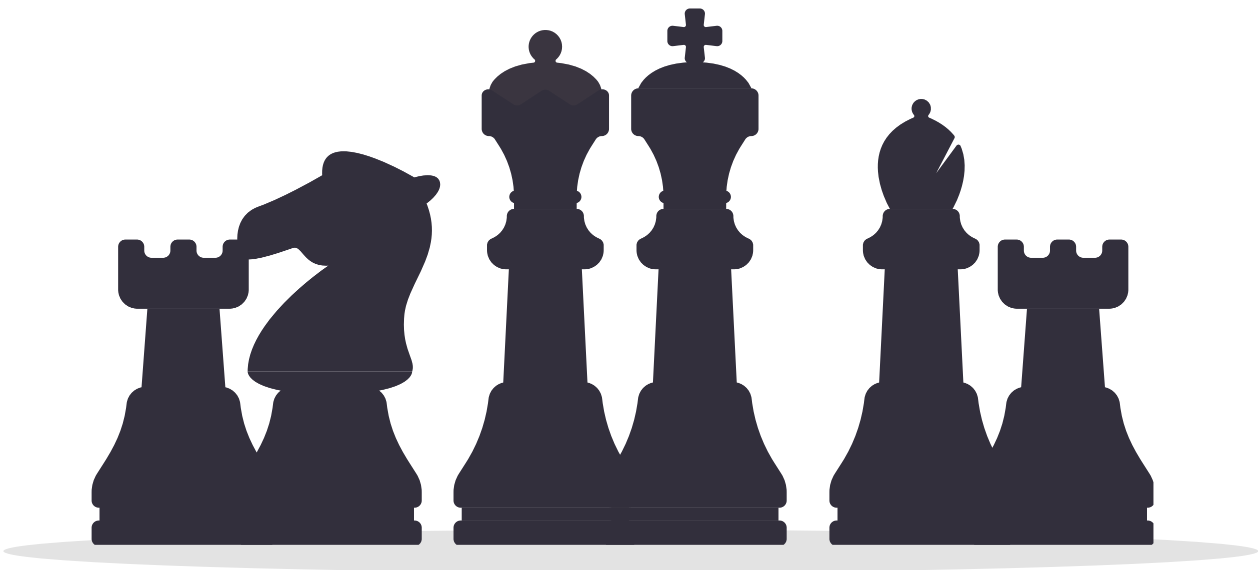
Forming a strategy for the future resembles creating a concrete action plan that will provide advocates with clarity about their duties, target population (patient group), and how to succeed. It helps advocates stay on track and reach goals that are true to their brand.

A strategy can be implemented on all different levels and corners of advocacy. It can be used internally to translate a common goal into objectives that can be carried out, or externally to communicate and lobby a high-level goal or provide guidelines for creating content for social media channels. In this way, advocates in all levels of shared work will be on the same page and work with one shared goal in mind.

2.1. A. WHAT IS A STRATEGY?

A strategy defines an advocate's area of focus, gives guidance on how advocates can locate assets and resources, and helps advocates create a scope for what is outside their capability or focus.

A strategy can be seen as a process to define an advocate's long-term direction but depending on the level of his or her strategic plan, it can also determine daily tasks and duties. Most strategic plans are divided into three sections: short (1-2 years), medium (5 years), and long-term (15 > years).



STRATEGY PLAN

Advocates can use the following template to organize their strategy plans.

MISSION	
VISION	
VALUES	
GOAL	

STRATEGY	TACTICS	MILESTONES
OBJECTIVE		

2.1.B. MISSION, VISION, VALUES

To effectively work as a team towards a common goal, there are three elements that should be articulated: a mission statement, a vision statement, and shared values or beliefs. The mission and vision statements are living documents that need constant evaluation on how they are interpreted and carried out. Advocates can fall back on their mission and values to create long-term goals and guide their employees, and their vision can be used to create strategic short-term planning and set up milestones that can be celebrated when reached.

The fundamental purpose of strategic planning is to align the mission of a company, group, or organization with its vision. Without mission and vision, the plan exists in a vacuum, as the **mission is the starting point for planning, the vision is the destination, and the strategic plan is the roadmap** that helps advocates navigate from one to the other. Developing vision and mission statements and sharing values are crucial practices toward the success of a advocacy strategy plan.

2.1. C. MISSION STATEMENT

The aim of the mission statement is to shed light on advocates' purpose as well as their roles for customers, employees, and the world. It focuses on the present, and what advocacy must achieve to make things possible. A mission statement is an opportunity to explain goals, norms, and values for decision-making. A strong mission statement serves multiple functions by helping advocates define objectives, live for a long time, and serve as a guide toward a common end-goal.

For creating a mission, advocates should answer the following questions:

- What do we do?
- Who do we advocate for?
- How are we helping them?

2.1. D. VISION STATEMENT

A vision statement represents the strategic aspect that defines the intended future goal of an advocate. A vision focuses on the future and the desired outcome of the advocacy. It describes specific objectives that help set priorities and choose where to invest resources. A well- established vision statement provides a framework for decision-making by sketching a desired future state that helps in long-term strategic thinking.

To craft a vision, advocates should ask themselves the following questions:

- What are our hopes and dreams?
- What problem are we solving, and for whom?
- Who and what do we hope to change?

2.1. E. VALUES

Values are core definitions or keywords advocates believe are important. By Ok. You can say integrating values, advocates define priorities that assist in good decision-making. If advocates' values are shared by the community, it drives a desired culture. For advocates to define their values, they should identify the time they were happiest or most proud of themselves or their organization. How did this experience make your life meaningful? Usually, organizations have around six values. Keep in mind that values can change and require evaluation and updating throughout the years.

2.2. DEVELOPING A STRATEGY

2.2. A. GOAL

To make an impact, advocates want to know the problem they aim to solve as well as their target population. This is the goal that defines what focus areas are essential for the success of their advocacy. A goal in a strategy usually describe the areas the organization will focus on to fulfill its mission which is advocacy in this case It can be that advocates have multiple goals for multiple stakeholders; if so, it should be made clear in strategy documents by adding chapters and topics.

2.2. B. OBJECTIVES

The goals and objectives of advocacy are to facilitate change and the development of new areas of policy, in order to tackle unmet health needs or deal with emerging health needs in a given community. A goal is the desired result of any advocacy activity.

2.2. C. STRATEGY

After developing objectives, advocates must define their solutions under the scope of a mission and vision statement. Questions to be self-addressed include: What do I need to change or accomplish to meet those objectives? How do I measure success? What are my key performance indicators?

2.2. D. TACTICS

Advocates should break down strategies into tactics by placing the stepping stones towards implementing the strategy. How are you going to do this? Assign certain employers or people to this task to create responsibilities and working groups.

2.2. E. MILESTONES

Milestones are small but steady victories that enable advocates to share success stories and validate their tactics. They are tangible results of long-term objectives.

2.2. F. EVALUATION

The strategy plan is process rather than a single solution or pathway. Regular meetings are necessary to evaluate the mission and vision document, sharpen goals, redefine tactics, and achieve milestones. Advocacy will grow and evolve, keeping in mind that advocates' goals and objectives may change too. The same applies for society and technology: It keeps developing.

The following example highlights the importance of setting a well-defined strategy based on values, goals, and objectives to further develop a specific action plan towards achieving desired objective.

A CASE STUDY ON PATIENT ADVOCACY / PATIENT ADVOCACY STRATEGY

Lebanon has been passing through multiple catastrophic crises since October 2019. The devaluation of the Lebanese pound, along with the unofficial capital control and shortage of foreign currency, continues to pose a threat to the importation and affordability of essential commodities. Since then, patients have been facing shortages in life saving medications and potential unaffordability due to lifting of subsidies on some classes of drugs.

The CME Office at the American University of Beirut supported the development of a **Patient Advocacy Strategy** with many active PAGs for sustainable access to cancer, hemophilia and multiple sclerosis pharmaceutical medicine in Lebanon through:

1- Building and developing a strategy by setting values, goals, and objectives

VALUES:

- Access to medicine is a human right and some countries incorporate it in their national constitution.
- Continuous access to medication is crucial to ensure health equity and advancing towards Universal Health Coverage (UHC).

GOAL:

Achieve the demand of patients and PAGs in terms of putting pressure on officials, decision-makers, and the Parliamentary Health Committee to respond to the demand to keep subsidies on selected medications and to sustain its provision in Lebanon.

OBJECTIVES:

- Create awareness of the cause
- Provide data and evidence-based argumentations
- Offer examples and international experience
- Emphasize the positive outcomes of goal achievement

2- Identifying potential influencers of this plan and their characteristics

3- Ensuring effective communication that reaches decision-makers and influencers to gain support

4- Directing key messages supported by data and evidence to decision-makers

CONCLUSION

Strategies can be implemented in different levels and corners of advocacy. In this specific case study, it was used externally to communicate and lobby a high-over goal and provide guidelines for creating content for efficient communication (addressing policy makers or social media audiences).

In this way, all levels of patients and PAGs involved will be on the same page and will work with one shared goal in mind.

2.3. MAPPING THE ENVIRONMENT

To be a successful advocate, one needs to recurrently innovate by looking at opportunities to expand one's network. Identifying and creating new opportunities to carry out a strategy is essential for achieving the organization's goals.

Stakeholder mapping is the visual process of laying out all the stakeholders of a product, project, or idea on one map. The main benefit of a stakeholder map is to get a visual representation of all the people who can influence the project and how they are connected. It is an essential step for an advocacy case success.

Below, one can find tips, a target audience template, and an empathy map that will help you achieve an efficient scan of the environment for the success of the strategy.
In addition, SWOT analysis presented below, will position an advocate to seize opportunities and prepare effective strategies.

Getting a clear and realistic view of the internal environment will help one identify ways to better satisfy patients' needs, achieve objectives, and strengthen weaknesses that have an impact on advocates' performance.

2.3. A. LISTEN

The best way to learn is through listening, especially when it comes to mapping opportunities. What are the patients experiences on this? Their needs, and challenges? What have they tried doing, but failed? What did they like or not? You can either do this via a formal interview, or an open informal conversation.

Use the insights to further define the **target audience**'s personal pains and gains.

2.3. B. BENCHMARK

Advocates should keep inventory of their competitors and fellow advocates and analyze their strategies. What are they doing (or not), and how are they doing it? Analyzing competitors will help advocates identify and develop opportunities to expand reach.

2.3. C. TRENDS & INSIGHTS

Advocates should subscribe to industry publications, join patient groups, keep a sharp eye on politics and governmental changes and set Google alerts for terms in their field of interest. In addition, they should follow other experts on social media and immerse themselves to keep up- to-date on the latest news and developments.

TARGET AUDIENCE

PURPOSE

A target audience is a specific group of people with shared interests, goals, or characteristics who are most likely to benefit or be interested in advocacy. By defining a target audience, one becomes more familiar with it and can focus the strategy, tone, and content of the message. This tool gives insight on who the target audience and how to understand what they need.

WHAT IS A TARGET AUDIENCE?

First, a target audience is not the same as stakeholders. Audiences are receivers of the message; advocates disseminate a message with the goal for them to receive it. Stakeholders are people or organizations that are impacted by the decisions or actions organizations make, which results in their active participation in reputation management. The goal of this tool is to define who messages should be sent to for awareness.

IDENTIFY A TARGET AUDIENCE

DEFINE THE CHALLENGE

Advocates should start with defining the challenges, or the problem that they want to solve in their advocacy efforts. This gives insight into the people that are presently suffer and who will benefit when this problem is solved.

CONDUCT RESEARCH

Advocates can research websites and social media profiles from competing with advocate groups in the communication on the social medias to sketch a picture of who they are communicating to. Determine the scope of the target audience: Is it broad (e.g., the global SMA community) or a niche market (e.g., the French Duchenne families)?

To determine identification of a target audience, one can answer the following questions:

- What is the problem you want to solve?
- Who is most likely to suffer from this problem?
- Who are competing with advocate groups in the communication on the social medias?

ANALYZING A TARGET AUDIENCE

To gain a deeper insight into a target audience's motivations and behaviors, an Empathy Map can be used. The map can be used to analyze a target audience and is originally created by Dave Gray. It can represent a group of users, just like a user persona can do. You can do this as an exercise in a group or create this during multiple conversations with your target audience, creating an overview of their needs and thoughts.

EMPATHY MAP

EXERCISE

Get a team together, and ask them to bring any pictures, data, or insights about the target audience. Print out or sketch the Empathy Map template and start by writing down the name of the team members in the middle of it; add demographics and describe him/her with keywords. Place a picture in the middle to give the target audience a face.

THINKING & FEELING

Next, fill in what the representative is thinking and feeling. Try to describe her/his attitude and behavior, how she/he behave towards others. Try to be as specific as possible to create a tangible person.

- What triggers him or her?
- What really matters?
- What are her/his worries, aspirations?

HEAR & SEE

- What does this person hear in her or his environment?
  This can be with friends, family or in the media and advertising.
- What does she/he hear from friends/family/colleagues/influencers?
- What do influencers say to her/him?

SAY & DO

Next step is to determine how this person influences others. Try to answer the following questions:

- What is a typical quote from her/him?
- How does she/he behave towards others?
- What is her/his attitude?

PAINS & GAINS

When the upper side of the Empathy Map is filled, you can analyze and define the frustrations, obstacles and emotional or functional needs the persona needs. Questions that can help with this include:

- What frustrates him/her?
- Where would he/she like to be?
- Where is he/she moving away from and towards to?

VALIDATION

With the outcome of this exercise, you will have a better understanding of your target audience's needs and behaviors. It is best to have multiple Empathy Maps since oftentimes there is more than one target audience to focus on. The final step is to talk to the target audience and validate the persona you created. Based on their feedback, you can further define the persona. Use the persona to review your strategy and objectives and evaluate if there are any misalignments that need to be addressed, and if any needs are still unmet.

2.4. STRENGTHS & CHALLENGES (SWOT)

To gain insight on the internal and external factors that can affect advocacy, the SWOT analysis is a powerful tool. This tool enables one to identify internal (e.g., financial resources, location, employees, legal elements) and external (e.g., demographic and economic trends, relationships with industry and regulators) areas for improvement, which can be useful for exploring opportunities.

STRENGTH

- **What advantages do you offer?**
- **How does your reputation, experience or history strengthen your ability to adovocate in this situation?**

List the strengths that can contribute to achieve your goals. Approach strengths from internal and external perspectives, ensuring you don't overestimate yourself.

WEAKNESSES

- **What are the general disadvantages in your advocacy strategy?**
- **What resources and capacity gaps do you have?**

It can be a challenge to answer weaknesses, as you oftent don't see your own, or you turn a blind eye towards them. Have others assess your weaknesses to identify gaps.

OPPORTUNITIES

- **What are intersting trends that you could respond to?**
- **What are the advantages of engaging in such an exercise?**

You might conduct research to answer these questions, considering trend research, economical or technological developments, or industry updates.

THREATS

- **Which relationships are at risk while engaging in certain advocacy tactics?**
- **What is your financial situation, and how can new technologies pose a threat to you?**

Any obstacles that can potentially influence your advocacy negatively are listed here.

2.5. BUILDING A TEAM

When building an advocacy team, identifying the right people to join is crucial. Balancing the team so that skills are shared across people will allow to cover gaps in the team leader's knowledge and abilities.

2.5. A. TEAM LEADERS

Advocates should focus on the strengths of their team. If fellow advocates become disillusioned or suffer from burn-out, remind them of their strengths, the wins you have scored from their work, and why they are important to the effort.

Some important skills to look for to create a balanced team include:

- Communication skills
- Writing skills
- Ability to use numbers or dealing with numbers
- Organized
- Self-motivated
- Approachable personality
- Works well in a team
- Responsible
- Proactive
- Firm in the face of rejection

It is not important for all these skills to be present in one or two people as by spreading them across the team will minimize disruption caused by attrition. In any case, team leaders should investigate the motivations of the people joining the team.

2.5. B. MANAGING TEAM CONFLICTS

Teamwork and collaboration are inevitable in patient advocacy. All work towards a shared goal and need each other to achieve more than team leaders can do alone. However, successfully working together in a team comes with challenges. There can be barriers or conflicts that do not necessarily need to form an obstacle for the teamwork if they are managed correctly and in time.
The following presents a few tips for managing team conflicts:

1. Ensure all are working towards a common goal. If the shared vision is missing, it is hard to be aware of the intended result.
2. Create space for discussion to ensure everyone's voice is heard. Make sure all perspectives are respected and understood.
3. Find underlying patterns and solutions together.
4. Locate resources and capacity to solve this conflict and put effort in finding and testing various solutions.
5. Celebrate conflicts that are solved and address any bottlenecks to ensure these conflicts are avoided in the future.

2.6. FINDING PARTNERS

Finding partners means finding like-minded people who will help the cause and support each other in evaluating ideas. To advocate widely, advocates should find the national representative group of the issue/cause being advocated for and join their events to connect and network. If there is no such representative organization, advocates may consider setting one up themselves. It can be as informal as a Facebook group and will build over time to provide an important resource for all the members.

All advocates know that they cannot work alone. However, they might find themselves doing the work alone. Having a few friendly ears to share thoughts with can offer new ideas and release built-up stress. There are many online forums and platforms where advocates can find like-minded people to share thoughts, ideas, and experiences.

A few tips for advocates on finding a "tribe" and finding the benefits of connecting to like-minded people include:

- **Connecting with people with the same intentions.** These can be other advocates or empowering entrepreneurs.
- **Discovering passions and interests**. What makes advocates happy and fills them with pride?
- **Knowing one's worth.** Nurture confidence rather than constantly comparing oneself to others.
- **Avoiding judgement.** Create space for exploration and self-reflection that can lead to unexpected friendships and collaborations.
- **Being proactive.** Approaching others offers great potential and is low-risk!
- **Being vulnerable.** Sharing one's vulnerable side will allow for genuine connection on a deeper level with a select group.

2.6. A. PARTNERSHIPS AND COALITIONS

Partnerships and coalitions are vital assets which can help work progress and communication spread further. They help lend credibility to smaller organizations by having the backing of a larger, more well-known one. They can also widen a network to reach desired communities.

- Formal or informal
- Long or short term
- Single or multi-stakeholder
- With or without financial support

Partnerships can also involve the sharing of knowledge and information, joint planning, organization of events or conferences, and consultation. Partnerships should be considered strategic; it is not a wise move to form an alliance with everyone who requests it.

2.6. B. CHOOSING PARTNERS

Creating a partnership takes time and research. That is, it takes hard work and trust-building to ensure a harmonious work environment together as well as protection of each other's interests.

Due diligence is necessary when choosing a partner and mapping out goals for the partnership. It is important to consider common goals and objectives as well as differences in approach. Writing down thoughts on the potential synchronicity of the partnership will help make good choices.

Advocates should not cut ties with potential partners if they are not a match now; they could be in the future.

2.7. STAYING ORGANIZED

Good organization will save time and energy and is vital to advocacy. To create a timeline and capture all the information to map a plan and project, a Project Initiation Document can be used. This template can be the basis for managing and evaluating the overall success of a project and cannot be changed after it has been approved by all stakeholders involved.

PROJECT INITIATION DOCUMENT

PURPOSE

A Project Initiation Document (PID) can form the foundation for many research projects. This document is created in advance and can be a reference point during the project for the team. It is also a decision document, so you can see who has to do what and in which time frame.

PROJECT INFORMATION

Background and occasion of the project, which together provide information about the context.

Name			
Date		**Draft / Final**	
Author			
Owner			
Client			
Document Number			

Revision History

Summary of Changes	Changes Marked

Approvals

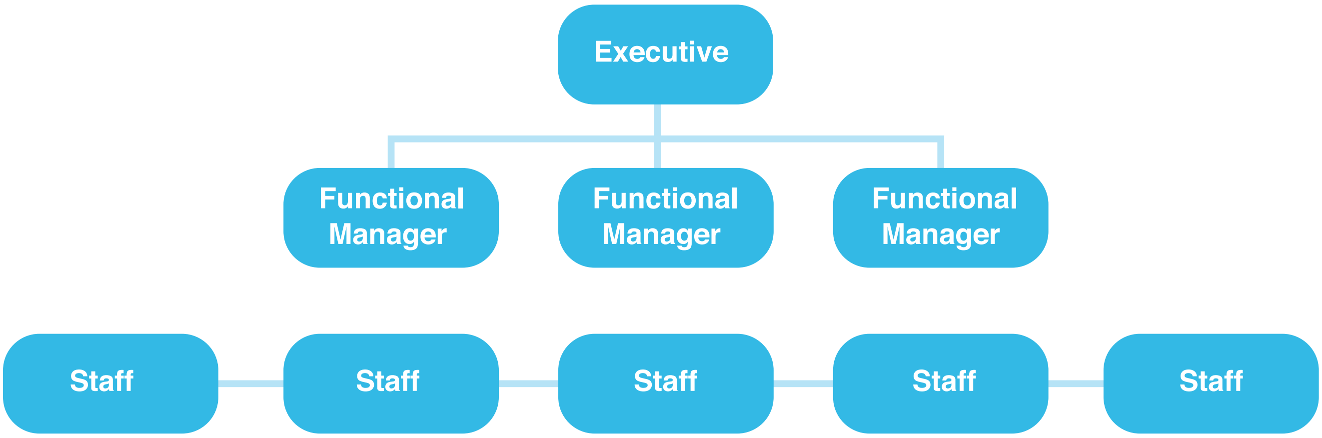
Title	Date of Issue	Version

Key roles and responsibilities

Role	Responsibilities

Organizational Structure

A description of management roles and responsibilities in the project.



Project Planning

The project planning exists in an Excel spreadsheet,
listing the duration of the project, and the activities that should occur.

Week						
1	2	3	4	5	6	7

Risk Log

The risk log includes measures that will be taken when there are unforeseen risks.

Owner	Action	Progress	Status

References & Resources

PROJECT INITIATION DOCUMENT PID - PROJECT-MANAGEMENT-SKILLS.COM

By identifying participants and stakeholders in the organization, advocates can influence how resources are obtained and managed. By completing a stakeholder analysis, advocates identify who stakeholders are to map their power, influence, and interests to know who they should focus on. When advocates gain a deeper understanding of their most important stakeholders, they know how and when to communicate with them to win their trust and support.

A guide for how to conduct Stakeholder Management can be found here:

- Create a filing system, be it digital, hard copy, or both, and stick to it. Store information inside this filing system to make sure all the necessary information is at hand.
- Keep all paperwork, especially anything to do with funding. Should funding be called into question, keeping organized will ensure easily accessible proof.
- Request stakeholder agreements in writing, whether in an email or a letter. Spoken agreements are of no value in advocacy work.
- Give professional tone to the advocacy work by using formal letterhead including a logo, whether digital or hard copy.
- Keep copies of important letters.
- Incorporate an effective internal communication system/platform.

STAKEHOLDER MANAGEMENT

PURPOSE

Stakeholder analysis is the first step in stakeholder management: a process that helps advocates manage time and resources to ensure that projects have succeeded. By identifying who is involved in an organization, advocates can leverage resources and time in managing them.

By conducting a stakeholder analysis to ensure productive collaborations, stakeholders are identified to map their power, influence, and interests. When a deeper understanding of the most important stakeholders is gained, the result is clearer communication to win their trust and support.

WHAT IS A STAKEHOLDER?

A stakeholder is a person, company or organization that is involved in making important decisions that influence another organization. Some of them have the power to advance another organization's work while others can block it. Their position, interest, degree of involvement and role are all factors that enable them to make decisions. The resources that they bring are vital: money, knowledge, a network of other stakeholders, or expertise.

IDENTIFICATION

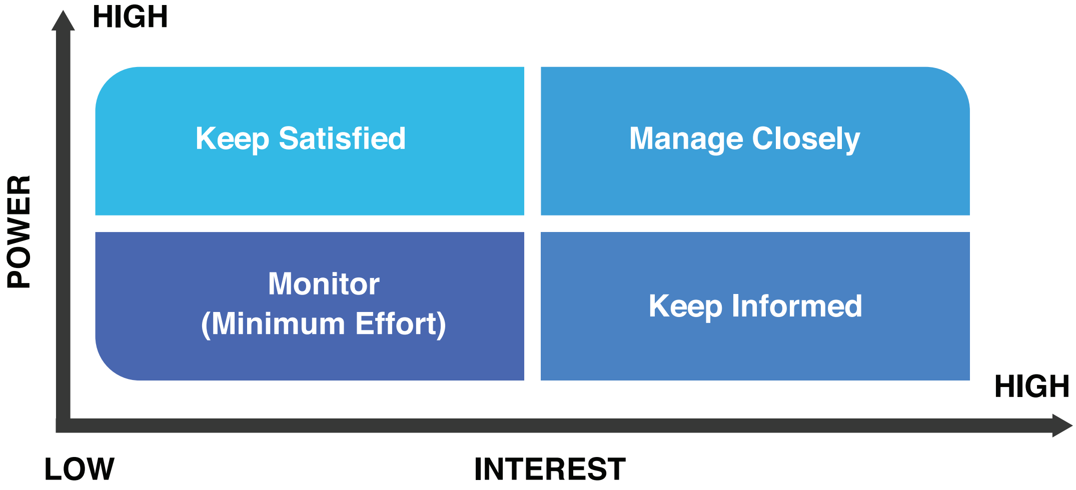
Start in a group by brainstorming and making a list of all people involved in the organization.

Questions that may help realize this include:

- Who can influence the way we operate?
- Who can impact/be impacted by our organization?
- Who can help us understand our issue/challenge?
- Who is interested in our success?

PRIORITIZATION

Now that there is a list of all people and organizations that are affected by the advocacy work, the next step is to map stakeholders by the level of importance or influence they have. Some people and organizations have the power to either counteract or cooperate; working closely with them will restrict the damage or boost their impact. A tool to prioritize stakeholder communication is the Power/Interest Grid.



References & Resources: MINDTOOLS

High power, highly interested

High power, highly interested people are key players that advocates want to manage closely. They can impact an organization greatly, so it is important to work closely and professionally with them. Invite them to meetings or co-create sessions so they have a platform to be heard. Examples of key players are investors, expert patient advocates, and pharmaceutical companies.

High power, less interested

Although high-powered, these people or organizations may be less interested in one's advocacy work but still want to stay informed on the progress. This type of stakeholder is often low in time and must use its resources sparingly, such as clinicians and regulators. Keep them in a close loop with your communication to ensure they are not forgotten and provide them with regularly updates to meet their needs.

Low power, highly interested

Low power, highly interested people are very engaged and can become brand ambassadors for one's advocacy. Although their impact may not be as significant as high impact people and organizations, it is important to show consideration and communicate the progress of a project or goal. Patient families and influencers in this field can be very helpful with creating word-of-mouth and help in disseminating advocates' messages.

Low power, less interested

Low power, less interested people should still be acknowledged as one of an advocate's stakeholder groups, which can consist of family members of a patient and healthcare practitioners. Keep them up to date about the project but do not waste too many resources (mostly time and money). Keep in mind that excessive communication may be perceived as too aggressive.

UNDERSTANDING

By empathizing with stakeholders, advocates get a better sense of their viewpoints and actions so they know how to communicate and manage them. The best way to do this is by asking them those questions directly, via an interview or an open discussion. People are often happy to share their standpoint and asking them for their opinions or worldviews is often the first step in relationship-building.

Key questions to ask stakeholders to better understand them:

- What interest do you have in our field or organization?
- What is your current opinion on our work?
- How would you like to stay informed about us?
- What motivates you?
- Who influences your decisions?

DISCUSSION

This stakeholder analysis can be used to define new goals or sharpen existing ones. Advocates can reflect on their stakeholder analysis, asking the following questions:

- What observations or impressions do we have when looking at the grid?
- What actions should we take to affect those things our organization can influence?
- How should we relate to those things in our circle of concern that we have little or no influence over?
- How might we re-evaluate our priorities based on this stakeholder analysis?

References & Resources

MINDTOOLS - CIRCLES OF INFLUENCE - INFLUENCE MAPPING

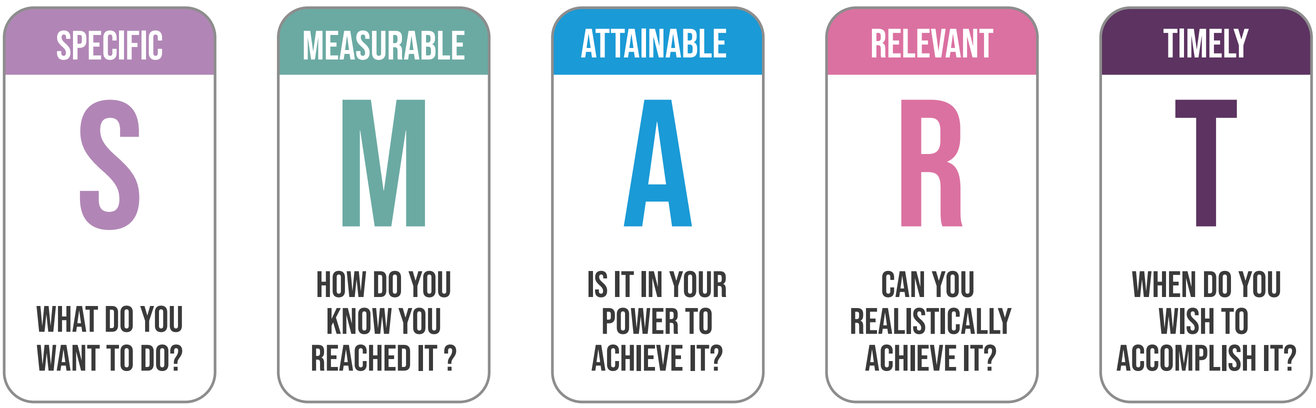
2.8. ESTABLISHING GOALS AND OBJECTIVES (SMART)

Advocates are trying to effect change for the benefit of a represented group. They can use the SMART model to identify goals.

SMART is an acronym for Specific, Measurable, Acceptable, Realistic, and Time-bound and is a method used to give directions to what advocates want to achieve and provides clear and simple guidelines for defining and managing goals and objectives. A key takeaway of the SMART formula is that it requires concision in communicating desired achievements, leaving no space for vagueness or interpretation.

Once SMART goals are in place, consider splitting them into long-term goals and short-term goals. The long-term goal should be the ultimate desired result, such as universal access to a new drug within the next five years for the entire patient body. Short-term goals represent the smaller steps that advocates need to take to reach the long-term goal, such as access for a high-need group of patients within the next year.

How long it takes advocates to reach their goals will depend on how well they have defined them and how clearly they have outlined the path to reach them. Achievability and timeliness will be key to this.



PURPOSE

Creating a strategy with mission, vision, goals, and objectives is one step. Bringing it into action and putting it into work in advocacy is the next step. Creating concrete steps to match strategy and measure success is not only a powerful tool to make process tangible, but it also creates credibility and trustworthiness towards stakeholders and gives advocates space to reflect on progress. The most well-known method to realize ideas while staying focused on effort and time is by using the SMART technique.

HOW TO DO A SMART ANALYSIS

SMART is an acronym for Specific, Measurable, Acceptable, Realistic, and Time-bound and is a method used to give directions to what advocates want to achieve and provides clear and simple guidelines for defining and managing goals and objectives. A key takeaway of the SMART formula is that it requires concision in communicating desired achievements, leaving no space for vagueness or interpretation.

SPECIFIC

Formulate your goal as precisely and specifically as possible. This can be a desired behavior, action, or result. Try to avoid using jargon: a goal must be understood by anyone. It preferably links to a number, amount, or percentage. Helpful questions:

- What do we want to accomplish?
- Who and what are we involved?
- When is the deadline?
- What is essential to make this a success?
- Why is this goal so urgent?

MEASURABLE

Without any progress made visible, there is no way to evaluate whether a goal is accomplished. Involve a way to determine whether a specified number is measurable and set a benchmark or baseline measurement to track improvement. Try to answer the following questions:

- How do you know the goal is achieved?
- What efforts do we have to make?
- How can it be measured?

ATTAINABLE

In other acronyms of the SMART model, the A stands for Assignable, Ambitious, or Acceptable. However, the underlying theme is similar: Goals only work when they are supported by all people involved. This should always be done with their consent, and everybody should be comfortable with the level of ambition: too high can be too stressful, while goals low in ambition result in a decrease in challenge and motivation. Answering the following questions may help map stakeholders and responsibilities:

- Do we all agree this is the goal?
- How is the goal accomplished?
- Who will be involved in this?
- What are concrete steps to take to accomplish this?

REALISTIC

Advocates' SMART goal is part of the strategy and aligns with the organization's mission and vision and the goals of stakeholders. A realistic goal is feasible and must be relevant for all those who are working on it, having the right resources in time, money, and capacity. Questions that may help with the relevance of the goal are:

- Is it a worthwhile goal?
- Do we have the right resources to start this?
- Does this goal align with my mission and vision?

TIME-BOUND

The last aspect of a SMART goal is that of time. Create a clear beginning and end time of the goal. "One year" might seem like a goal, but by specifying a date on it (e.g., one year from now, so on XX Month Year) the goal becomes more tangible. It is wise to create enough space for unforeseen circumstances and an increase of motivation (one cannot always be fully motivated). If there is a big decrease in motivation, a goal might not be achievable and realistic enough. Questions that may help define the time include:

- How long will accomplishing this goal take?
- When am I going to work on this goal?
- When is the completion of the goal due?

EVALUATION

Advocates should write down SMART goals and use them in their strategy. These can be referred to every now and then to evaluate progress toward achieve their goals. This can be done individually or with employees and stakeholders to engage with them and create or redefine strategy and goals.

References & Resources

SMART GOALS - ESSENTIAL GUIDE:WRITING SMART GOALS - SMART GOALS EXAMPLES

This is an example of an advocacy group developing SMART Goals for an Advocacy Campaign.

EXAMPLE OF SETTING A SMART GOAL

It is November 1, 2016. A group of self-advocates with intellectual and developmental disabilities is having its monthly meeting. The self-advocacy group has just found out that the local public transit authority plans to scrap disability fare cards starting in February 2017. The public transit authority will be holding board meetings and public interest hearings before the decision, which is final on January 13, 2017. This decision will hurt many people with disabilities who rely on public transit. Some people with disabilities might be deterred from taking public transit if the fare increases.

The self-advocacy group's president asks the members of the group their opinions on creating an advocacy campaign to prevent this from happening. The group decides they want to take this on. They decide to use SMART goals to create an action plan for their campaign. One member suggests a goal of organizing a boycott of public transit. But someone else says that this might not be achievable. Many people use the transit and many of those would be unable to boycott due to monetary or disability related reasons. Another member suggests organizing a phone call and letter writing campaign. The group likes this idea, so they go through aspects of the goal to make sure it is a SMART goal. When they are done, their SMART goal reads: "Our group will organize a phone call and letter writing campaign to the 10 transit authority members and director by people with disabilities, our families, and other allies. At least 25 people will make calls and write letters. The campaign will be completed by January 13, 2017."

Why is this goal a SMART goal?

SPECIFIC

The goal specifies in detail the group's action plan including who they will work with and who is the target of their action.

MEASURABLE

The goal is measurable because it includes a specific number of people who will participate in order to meet it. By keeping track of how many people have made calls or written letters, the group will be able to measure how closely they are to meeting their goal.

ACHIEVABLE

Preventing the transit authority from following through with their decision is attainable because the focus is local and has a concrete objective.

REALISTIC

The goal is realistic because the group has a big enough network to get many people to call and write letters.

TIME-BOUND

The campaign has a nearly two-and-a-half month lifespan and can be made further time-bound with mini-goals deadlines. Ultimately, they must finish the overall goal of the phone call and letter-writing campaign by January 13, 2017.

Mini-goals for the phone call and letter-writing campaign:

- **November 15:** The website will have a page with a press release about the decision that encourages people to act by participating in their phone call and letter campaign. The statement will include contact information for the transit authority members and director, and specific scripts for calling and writing as well as the dates for two coordinated days of action.
- December 1 and January 2: **Two coordinated days** of action for people to participate in the campaign.
- **November 22:** The group will have used the campaign to request private meetings with the transit authority director.
- **November 28:** Group members will have contacted as many people as they can about the campaign to spread the word.

2.9. RISKS IN ADVOCACY

Advocacy does come with some risks, and it is important to become aware of these and map them. Leadership, collaboration, and communication are essential to act accordingly and minimize damage because even well-planned advocacy can be interpreted differently. There are several strategies that can be used to prepare for encountering any problems. The following form can be filled to analyze risk related to specific advocacy work.

TOOLS & TEMPLATE: RISK ANALYSIS

PURPOSE

In the field of advocacy, there are many risks and threats that may become a reality. However, if these risks are noticed in time and dealt with accordingly, the impact of the threat can be averted or minimized.

MATRIX

A tool to identify possible threats is the SWOT analysis. After risks have been identified, they can be plotted into a risk assessment matrix based on their possible impact. In this matrix, you can enter the risks to gain an overview of which threats and risks are prioritized. The Y-axis portrays the likelihood that the risk becomes reality, and the X-axis gives insight on how big the threat will have on your advocacy.

PROBABILITY IMPACT MATRIX

	Minor	**Moderate**	**Major**
Frequent	Medium	High	High
Likely	Low	Medium	High
Remote	Insignificant	Low	Medium

Based On : " TOOLSHERO "

MEASURES

After the identified risks have been rated and plotted on the severity of consequences it can have, different measures can be taken to avert or minimize the damage.

Avoid

A preventive way of managing risks is to avoid undertaking them at all. Another possibility will be to adjust the policy or process or to outsource it. This kind of measure is happening quite often to ensure advocacy does not carry too much risk.

Reduce

By addressing the cause of the threat, the risk is reduced. The measures to be taken are only to be used to limit the occurrence of the risk in question

Transfer

By transferring the risk, the policy or process is outsourced to shift the responsibility to another party.

Accept

If the risk is almost insignificant or does not compensate the positive outcomes, no additional measures have to be taken. Accepting a risk does not mean that the risk cannot be influenced: you can simply work on the risk later on.

RISK MATRIX

Likelihood		Very Likely	Likely	Unlikely	Highly Unlikely
Consequences	Fatality	High	High	High	Medium
	Major Injuries	High	High	Medium	Medium
	Minor Injuries	High	Medium	Medium	Low
	Negligible Injuries	Medium	Medium	Low	Low

References & Resources

DEVELOPING AND IMPLEMENTING THE ADVOCACY PLAN - IDENTIFY ACTION STEP - 10 EASY RULES TO REDUCE RISKS ON PROJECTS

2.9. A. ADVOCACY CAN BE RISKY

As with anything, there are some risks involved in advocacy. One of the largest risks is the involvement of the industry or political associations, the public actions, and events. This may affect the advocates' reputation, finances, and relationships with stakeholders, partners, or the government.

2.9. B. AVOIDING RISKS

A thoroughly planned advocacy approach should help advocates avoid confrontation in the first place. The following list includes examples of where risks can come from as a result of internal problems:

- Loss of funding
- Loss of staff
- Funding allocated wrongly
- Misspent funds
- Legal confrontations
- Technology risks

Advocates should ensure that during the planning stage, they have back-up scenarios in place for each potential outcome. Budget planning should not be designed as if you have the funds in the bag. Always leave some room for a sudden loss of funds.

In addition, the legal requirements of the country you are advocating in should be investigated to ensure full coverage for even minor risks such as fire, insurance, permits, tax papers etc. A well-organized administrative system will help conflicts be resolved quickly.

Advocates should ensure that their computer equipment is functioning and has a good anti-virus system. Valuable and sensitive data should be copied and stored on a secure cloud system as well as on a physical drive to minimize disruption if software crashes. Always ask yourself, "How badly do I need this data?" and protect it accordingly.

Should the worst happen, advocates can fall back on backup files to get back up and running as quickly as possible.

To prepare budgeting for advocacy, the following Build a Budget template and example can be useful.

COMPANY NAME: DATE:

MONTHLY BUDGET

BUDGET TOTALS	ESTIMATED	ACTUAL	DIFFERENCE
Income	63,300.00	57,450.00	5,850.00
Personnel Expenses	18,500.00	14,100.00	4,400.00
Operating Expenses	18,500.00	14,100.00	470.00
Balance (Income minus expenses)	8,800.00	7,820.00	980.00

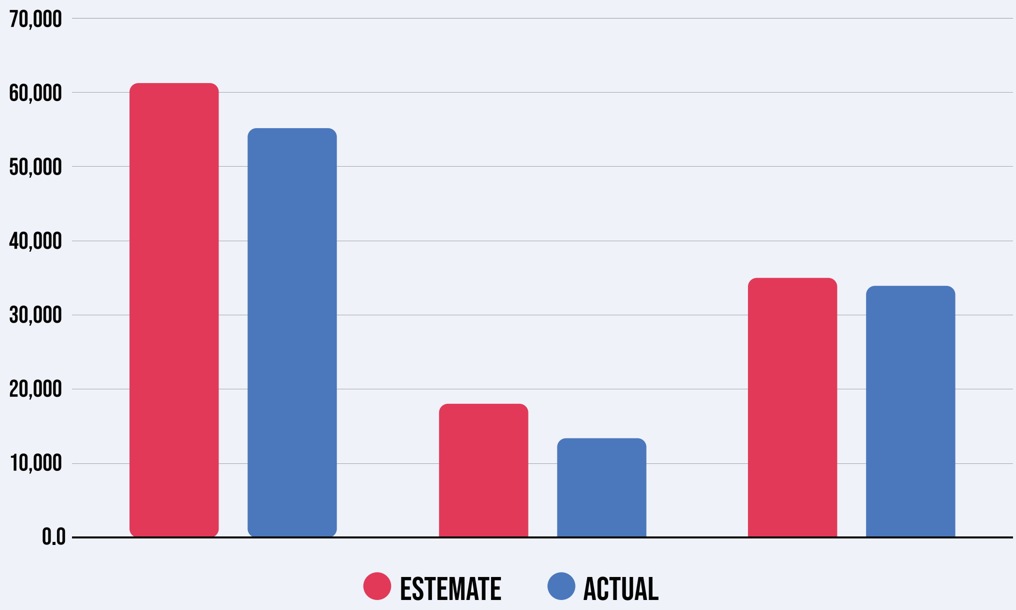
WHAT ARE MY TOP 5 HIGHEST ACTUAL OPERATING EXPENSES:

ACTUAL EXPENSES	AMOUNT	% OF EXPENSES	%15 REDUCTION
Maintenance & repairs	4,600.00	12.9%	690.00
Supplies	4,500.00	12.7%	675.00
Rent or mortgage	4,500.00	12.7%	675.00
Taxes	3,200.00	9.0%	480.00
Advertising	2,500.00	7.0%	375.00
Total	**19,300.00**	**54.3%**	**2,895.00**

MONTHLY BUDGET SUMMARY

Each organization should decide on the part of the budget to be used for advocacy depending on its total annual budget.

BUDGET OVERVIEW



COMPANY NAME: DATE:

MONTHLY BUDGET INCOME

INCOME	ESTIMATED	ACTUAL	DIFFERENCE
Net sales	60,000.00	54,050.00	6,000.00
Interest income	3,000.00	3,000.00	0.00
Asset sales (gain/loss)	300.00	450.00	150.00
Total income	63,300.00	57,450.00	5,850.00

COMPANY NAME: DATE:

MONTHLY BUDGET PERSONNEL EXPENSES

PERSONNEL EXPENSES	ESTIMATED	ACTUAL	DIFFERENCE
Wages	9,500.00	9,600.00	100.00
Employee benefits	4,000.00	0.00	4,000.00
Commission	5,000.00	4,500.00	500.00
Total Personnel Expenses	18,500.00	14,100.00	4,400.00

COMPANY NAME: DATE:

MONTHLY BUDGET

OPERATING EXPENSES

OPERATING EXPENSES	ESTIMATED	ACTUAL	DIFFERENCE
Advertising	3,000.00	2,500.00	500.00
Bad debts	2,000.00	2,000.00	0.00
Cash discounts	1,500.00	2,175.00	(675.00)
Delivery Costs	2,000.00	1,500.00	500.00
Depreciation	1,000.00	1,000.00	0.00
Dues and Subscriptions	500.00	525.00	(25.00)
Insurance	1,300.00	1,275.00	25.00
Interest	2,000.00	2,200.00	(200.00)
Legal and auditing	1,000.00	800.00	200.00
Maintenance and repairs	4,500.00	4,600.00	(100.00)
Office supplies	800.00	750.00	50.00
Postage	400.00	350.00	50.00
Rent or mortgage	4,100.00	4,500.00	(400.00)
Sales expenses	350.00	400.00	(50.00)
Shipping and storage	900.00	840.00	60.00
Supplies	5,000.00	4,500.00	500.00
Taxes	3,000.00	3,200.00	(200.00)
Telephone	250.00	280.00	(30.00)
Utilities	1,400.00	1,385.00	15.00
Others	1,000.00	750.00	250.00
Total operating expenses	**36,000.00**	**35,530.00**	**470.00**

2.9. C. DEALING WITH RISKS

Accept that no matter how well advocacy is run, some risk comes with the territory. How can serious problems be addressed? The best approach is to collaborate with team members (if you have them) or other trusted advocates who do not have any stake in either what is being advocated for or the adverse scenario that the advocacy addresses.
When an approach is in place, it is best to resolve conflict at a lower level instead of escalating. For example, this may mean talking directly to the opposing party to resolve conflict and convening a meeting where both sides are equally represented.

Taking the issue directly to the media could backfire badly and should only be an extreme last resort. Even when responding to media exposure which an opposing party has initiated, remaining calm and reasoned in the face of their accusations will reduce the risk to your reputation.

The quicker and more low-key the solution, the more likely it is that even a hostile element can be kept in check. Nonetheless, serious issues (i.e., fraud, patient abuse, black marketing drugs) do require escalation and should be taken to a higher authority.

2.10. SELF-CARE IN ADVOCACY

Advocacy is important work that adds tremendous value to the patient community. Without patient advocates, much of the progress achieved so far would have been very difficult to achieve. However, it is also hard, slow, and often disappointing work. Working as a patient advocate with people with chronic and/or life-threatening diseases conjures ample obstacles such as rejection and doors shut in your face.

While crucial synergies are formed, relationships might fall apart unexpectedly. Furthermore, governmental changes that introduce new policies can derail progress. Or, a medical trial you had been heavily advocating for loses its funding. These are just a few scenarios an advocate can face in the arena of rare patient advocacy.

Such challenges can impact advocates' mental health. While taking care of the rare patient community, advocates must make sure to also take care of themselves. Self-care is an often-overlooked aspect in advocacy. One can easily forget about or dismiss his or her own wellbeing when hearing all the heart-breaking stories and unanswered requests as the planning piles up, driving advocates into stress. To help people, advocates must ensure their own physical and mental health
Self-care isn't selfish!
Below are some tips for coping with the pressure of advocacy which can be used individually or for teams:

1. Accept that it is alright to feel burnt out or that you have reached your limit; allow time to regroup your mental resources.
2. Disappointment is built into patient advocacy. Every success will come in the wake of several failures.
3. Keep goals realistic to limit the scope of disappointments.
4. Engage in space outside of advocacy; a hobby that's unconnected to the advocacy work is a good place to start.
5. If you find that you are constantly on call from others in the patient community, and that this is affecting your well-being, set limits in place, such as not answering calls after 9 pm or not checking emails after 8 pm. Keep in mind that this is not abandoning people who need you, it is ensuring that you have the energy you need to keep doing what you do.
6. Open up. Other advocates are great people to talk to when you feel burnt out.
7. Ask for help. If you are getting loaded with work, learn to delegate, even if you are a perfectionist.
8. Consider professional counselling as an advocacy tool, and use it from time to time to avoid burnouts, even when feeling fine.
9. Always remember the reasons behind starting the advocacy. If you are truly struggling, weigh up the reasons you started with and the reason to continue.

10. Even if you want to carry out your role alone, this will not always be possible. Check out if you can get some support from people in the same arena as you, such as an umbrella of advocacy organizations or a patient support group. There is no harm in reaching out to people who you think advocate effectively, and in asking for their advice, or even in seeing if they would be willing to mentor your effort until you set track in your work.

2.11. MONITORING & EVALUATION

2.11. A. WHAT IS MONITORING AND EVALUATION?

Monitoring is essential when developing a project. It is the process of following up with the activities throughout the whole advocacy project, providing support when needed and guiding the advocates toward the final objective. It is essential to follow up and supervise projects to ensure smooth accomplishment. In contrast, **Evaluation** is the process of assessing activities, milestones, events, regulation, and ensuring that other steps are being accomplished correctly in addition to being accomplished effectively.
To monitor and evaluate, an examination about the quality of the events or the documents generated is done by using pre-defined Key Performance Indicators (KPIs).

Monitoring and evaluation of initiatives on patient advocacy take place on different levels, depending on the goals and objectives of the program, the scope of activities, and strategies being designed or implemented. But both are essential to ensure the impact of a project to change the advocacy landscape.

2.11. B. HOW TO MONITOR AND EVALUATE

There are different processes that will facilitate monitoring and evaluation:

- Evaluate the (real) needs that the project will cover.
- Plan the strategy on expectations of how to reach the objective and plan the monitoring and evaluation process in advance.
- Clearly state the milestones of success and share it with the people involved, so all can understand and get involved from the beginning.

2.11. C. STARTING AND ENDING

Monitoring happens when the project has begun, but what about evaluation? Well, it is similarly important to evaluate before and after the project. If required to evaluate before, advocates should take stock of money, time, and effort. This can determine the feasibility of the project and facilitate decision making and future resource obligations.

By evaluating after the end of the project, different conclusions can be found as discovered during the advocacy implementation. Making projects sustainable over time when defects can be corrected is an assurance that must take into consideration to improve future project plans

3. IN A NUTSHELL: BUILDING THE FOUNDATIONS FOR A SUCCESSFUL STRATEGY

Successful advocacy starts with successful planning. Ideas are great to get a sense of direction. However, keep in mind that approaching an advocacy strategy with a dozen ideas will disrupt focus on distribution of resources. Success is more likely with only a handful of ideas to focus on, or better yet, one central focus. Reorganizing ideas will be a top priority for success.

The following steps will help set the groundwork on which to build and maximize advocates' chances of success.

3.1. CREATE A STRATEGY

Start with a central focus and the reason behind the advocacy. This will give you an idea of what is needed to be done. Next, set out concrete points and the flexible areas of the plan as well as the areas considered red lines (such as accepting funding from certain sources or working in collaboration with certain pharmaceutical companies).

3.2. RESEARCH AN AGENDA AND GATHER EVIDENCE

Advocates should focus on the message content and become familiar with who else is doing something similar. While it is great to use readily available resources, it is also important to take time out to look deeper into research, especially facts and figures. If another advocacy body has presented some data, check the source and go to the original document.

3.3. UNDERSTAND THE AGENDA ON A NATIONAL AND GLOBAL LEVEL

For an advocate, the cause is no doubt close to the heart. But can it be developed into a message to reach a wider audience? Assess the level of coverage and interest for the cause, locally, nationally, and internationally. This will give a sense of how to create an advocacy framework, including the messaging and how it can best be targeted.

3.4. WORKING IN PARTNERSHIP

During research, advocates may find umbrella advocacy organizations, which strengthen efforts and give more leverage. Another option is to join forces with another advocate or advocacy group and see if combining efforts can yield better results.

It is important to do research before entering any partnership. Different bodies and agencies have different agendas, and it is possible that they have several funding sources. Ask questions and do research to establish if your core interests and beliefs are aligned.

Working with all stakeholders is key, especially when interacting with pharmaceutical companies. It is important to follow same rules to perform work effectively and properly. To do it in the best way possible, advocates must develop their own code of practice. It is a dynamic document and can be updated as necessary.

The following case explicitly illustrates the power of partnerships. We can see how a PAG was able to strengthen its efforts by working in partnership with the drug manufacturer to ensure availability and accessibility of medications in any circumstances.

A CASE STUDY ON PATIENT ADVOCACY /PARTNERSHIPS WITH DRUG MANUFACTURER

CASE SCENARIO

A patient living in the Caribbean had been suffering from a genetic lung disorder from a young age and had found there were no effective treatments available in his home country. His local physician decided to refer the patient to a specialist in the US who prescribed him an FDA-approved prescription antibiotic inhaler used to improve breathing symptoms. However, the drug was not approved in the patient's country and there was no way of gaining access without travelling to and from the US for each repeat prescription, which was not feasible in the long-run. The patient's family, therefore, reached out to a local PAG in a desperate attempt to find a solution.

The PAG's first approach was to contact the drug manufacturer on the patient's behalf and request assistance. The manufacturer responded to say it has an access program in place for patients who cannot access the medication through normal channels. However, the program could only cover US patients, which meant the young Caribbean patient was ineligible.

As such, the PAG and the manufacturer worked together to set up a completely new access program for this individual patient. The manufacturer provided the drug, and the PAG worked with the local regulatory agency to gain import approval. The PAG then worked directly with the company's logistics partner to organize the delivery to the patient's local physician.

CONCLUSION

The manufacturer and the PAG now work together to send repeat deliveries to this patient every six months.

3.5. CONFLICT OF INTEREST/DECLARATION OF INTEREST

Conflicts of interest can arise from time to time. An example of a conflict of interest could be a situation where an advocate who is invited to speak at an event will be paid from a funding source that could damage the advocate's reputation (e.g., a cancer research advocate indirectly being paid by a certain pharmaceutical company).
Areas where conflict of interest can arise between two parties include:

- Employment
- Consultancy activities
- Funding sources
- Collaborations with other organizations
- Gifts given or accepted
- Hospitality given or received
- In-kind work, activities, or consultation
- Close family members and their involvement in areas that could be a conflict of interest

In this context, verbal agreements are not very useful. To keep strategies and visions clear for all parties, it is best to have a conflict-of-interest form to fill in and sign so that there is a concrete record of each party's agreement toward the advocacy.

By offering a Declaration of Interest (DoI) form for all collaborators will ensure clarity and transparency and protect the advocate's reputation.

DECLARATION OF INTERESTS

INSTRUCTIONS

This form consists of three parts: **Personal Details, Public Declaration of Interests**, and **Confidentiality Undertaking**. All parts must be duly completed. The form is designed to be completed electronically, printed, and sent to (Advocate's Organization) in pdf format. Advocates are responsible for the accuracy and completeness of the submitted information.
Please be advised that once the form has been signed and submitted, the (Advocate's Organization) will post declaration of interests on its (Advocate's Organization) website.

Advocates will be asked to provide an updated Curriculum Vitae which must be submitted simultaneously with the declaration.

SECTION 1: PERSONAL DETAILS

First name:
Last name:
Organization/Company:
Country:
E-mail address:
Role:

SECTION 2: PUBLIC DECLARATION OF INTERESTS

If you have interests to declare, please tick "Yes" to the relevant questions and provide further information. All questions in this section must be answered. Your declaration will not be accepted if any fields are left empty. All current and/or past interests from the last 3 years (where applicable) should be declared.

You may also provide information on interests over three years ago. This information, to be recorded under section **2.10 Any other interests or facts**, as well as any other interests or facts, will not be used in the evaluation of declared interests.

For more information on which interests to declare, please see the (Advocate's Organization) policy on the handling of competing interests of Management Board (MB) members.

I do hereby declare on my honor that, to the best of my knowledge, the only direct or indirect interests in the pharmaceutical industry I have currently (at the time of completion of the form) or have had (in the last three years) are those listed below.
I further declare on my honor that to the best of my knowledge, personal interests, other than interests in the pharmaceutical industry, which I currently have (at the time of completion of the form) are those listed below:

2.1 EMPLOYMENT NO YES

Employment with a pharmaceutical company means any form of occupation, part-time or full-time, paid or unpaid, in the company.

2.2 CONSULTANCY NO YES

Consultancy to a pharmaceutical company means any activity where the MB member provides advice (including training on a one-to-one basis) to a pharmaceutical company regardless of contractual arrangements or any form of remuneration.

Note i: Scientific advice provided by the National Competent Authority NCA of a Member State is not considered a consultancy activity.

Note ii: If you are or have been an employee of a CRO or consultancy company (i.e., a professional business offering advice or services to pharmaceutical companies), please declare this under Section

2.3 STRATEGIC ADVISORY ROLE NO YES

Strategic advisory role for a pharmaceutical company means any activity where the MB member is participating (with a right to vote on/influence the outputs) in a(n) (scientific) advisory board/ steering committee with the role of providing advice/expressing opinions on the (future) strategy, direction and development activities of a pharmaceutical company, either in terms of general strategy or product related strategy, regardless of contractual arrangements or any form of remuneration.

Note: Involvement in Data Monitoring Committees fall outside the scope of this definition. Such involvement should be recorded under section 2.5 Principal investigator. Involvement in research for a pharmaceutical company should be listed under section 2.5 Principal investigator or 2.6 Investigator as appropriate.

2.4 FINANCIAL INTERESTS NO YES

Financial interests mean any economic stake in a pharmaceutical company including:

- **CURRENT** holding of stocks and shares, stock options, equities, bonds and or partnership interest in the capital of a pharmaceutical company with the exclusion of the holding of financial interests through an investment fund, pension fund and/ or interests in non-nominal unit trusts or similar arrangements provided that they are diversified (i. e. not exclusively based on the pharmaceutical sector) and they are independently managed (i.e. the individual has no influence on their financial management).

- **CURRENT** compensation, fees, honoraria, salaries, grants, or other funding (including rent, sponsorships, and fellowships) paid by a pharmaceutical company to you in a personal capacity, other than payment for or reimbursement of expenses incurred with research work or reimbursement of reasonable expenses directly related to conference/seminar attendance (i.e. accommodation and travel costs).
- **CURRENT** intellectual property rights including patents, trademarks, know-how, and/or copyrights relating to a medicinal product owned by you or of which you are directly a beneficiary.

Note: Attendance at courses and conferences funded by pharmaceutical industry (including attendance at accredited courses or conferences with respect to Continuing Professional Development (CPD)/ Continuing Medical Education (CME) acquisition whereby the MB member receives payment by pharmaceutical industry going beyond reimbursement of reasonable expenses (i.e., accommodation and travel costs) directly related to a conference/seminar attendance need to be declared if current.

2.5 PRINCIPAL INVESTIGATOR NO YES

(**CURRENT** is interpreted at time of completion of this form)
Principal investigator (PI) means those with current responsibility for the coordination of investigators at different centers participating in a multicenter pharmaceutical industry instigated/ sponsored trial or the leading investigator of a monocenter pharmaceutical industry instigated/ sponsored trial, or the coordinating (principal) investigator signing the clinical study report. This definition does not include a national coordinating investigator in a multinational trial. Involvement in Data Monitoring Committees should be included in this section.

Note: Involvement in academic trials and publicly funded research/development initiatives involving pharmaceutical products as well as membership of an ethics committee, should be Included under section **2.10 Any other interests or facts**.

2.6 INVESTIGATOR NO YES

Investigator means those currently involved in a clinical pharmaceutical industry instigated/ sponsored trial at a specific trial site who can be the responsible lead investigator of the trial at that specific site or a member of the clinical trial team who performs critical trial- related procedures and makes important trial-related decisions.

Note: Involvement in academic trials and publicly funded research/development initiatives

involving pharmaceutical products as well as membership of an ethics committee, should be included under section **2.10 Any other interests or facts**.
(***CURRENT*** *is interpreted at time of completion of this form)*

2.7 GRANT / FUNDING TO ORGANIZATION / INSTITUTION NO YES

Grant or other funding to an organization/institution means any CURRENT funding received from a pharmaceutical company by an organization/institution to which the MB member belongs, or for which he/she performs any kind of activity, and which is used to support any activity of the MB member whether it is related to research work.
(***CURRENT*** *is interpreted at time of completion of this form.)*

2.8 CLOSE FAMILY MEMBER INTEREST NO YES

Close family member means first-line members of your family (i.e., a spouse or a partner, children, and parents).

Interests to be declared include **CURRENT** employment, consultancy, strategic advisory role, and financial interests. *(**CURRENT** is interpreted at time of completion of this form.)*

2.9 PERSONAL INTERESTS, OTHER THAN IN A PHARMACEUTICAL COMPANY NO YES

MB members should declare the following current personal interests:

- Interests in other entities possibly providing services to the Agency (i.e., in the areas of IT, infrastructure, catering), as well as interests in other areas such as medical devices/diagnostics/reagents not linked with medicinal products which may be discussed at the MB.
- Positions (either a managerial role or other influential roles) in a governing body (irrespective if such position is paid or not) of a professional organization with an interest in the field of pharmaceuticals other than a pharmaceutical company.

Note: If you belong to organizations such as patient, consumer, or healthcare professional organizations, and your organization receives grants or other funding from a pharmaceutical company please declare this under section ***2.7 Grant or other funding to an organization/ institution.*** *(**CURRENT** is interpreted at time of completion of this form.)*

2.10 ANY OTHER INTERESTS OR FACTS NO YES

- Involvement in academic trials and publicly funded research/development initiatives involving pharmaceutical products.
- Membership of an Ethics Committee (you do not need to state a list of trials you were involved in).
- If you work in an organization/institution where your colleagues provide consultancy advice to pharmaceutical companies, but you are not directly involved in the provision of such advice. Examples include employees of Official medicine Control Laboratories, staff members of academic departments, etc.
- Participation in European societies/research foundations/strategy boards/treatment groups/focus groups, which may be funded in full or in part from unrestricted grants from pharmaceutical companies (not from one single company), with or without involvement of industry participants and which may provide general advice (on development programs, clinical study design, strategy, etc.) to several pharmaceutical companies (not one particular company) in a specific therapeutic area.

Please declare any other interests below:

SECTION 3: CONFIDENTIALITY UNDERTAKING

In view of the following definitions:

"(Advocate's Organization)" encompass any meeting (including meeting preparation and follow-up, associated discussion, or any other related activity) of the (Advocate's Organization) Management Board, Committees, Working Parties, Expert Groups, or any other such meeting; work as an expert on assessments; work as an expert on guidance development.

"**Confidential Information**" means all information, facts, data, and any other matters of which I acquire knowledge, either directly or indirectly, because of (Advocate's Organization) Activities.

"**Confidential Documents**" means all drafts, preparatory information, documents, and any other material, together with any information contained therein, to which I have access, either directly or indirectly, due to my participation in (Advocate's Organization) Activities. Furthermore, any records or notes made by me relating to Confidential Information or Confidential Documents shall be treated as Confidential Documents.

I understand that I may be invited to participate either directly or indirectly in certain (Advocate's Organization) activities and hereby undertake:

- To treat all Confidential Information and Confidential Documents under conditions of strict confidentiality
- not to disclose (or authorize any other person to disclose) in any way to any third party*
- Confidential Information or Confidential Document
- Not to use (or authorize any other person to use) any Confidential Information or Confidential Document other than for the purposes of my work in connection with (Advocate's Organization) activities.
- To dispose of Confidential Documents as confidential material as soon as I have no further use for them.

**Third party does not include employees of the National Competent Authorities who either have employment contracts that provide confidentiality obligations or are encompassed by confidentiality obligations under national legislation on professional secrecy.*

I confirm I have read and understood the (Advocate's Organization) policy on the handling of competing interests of Management Board members and I agree to abide by the policy. I have read and understood the training material which has been provided to me.

I confirm that the information declared on this form is accurate to the best of my knowledge and I acknowledge that my information will be stored electronically and published on the (Advocate's Organization) website.

I undertake to submit an up-to-date Declaration of Interest and Curriculum Vitae at least on an annual basis and to update this Declaration and my Curriculum Vitae promptly should any changes occur, indicating additional interests that should be known to the (Advocate's Organization).

Full name:

Signature:

Date:

3.6. TIME FRAMES/TIMELINE

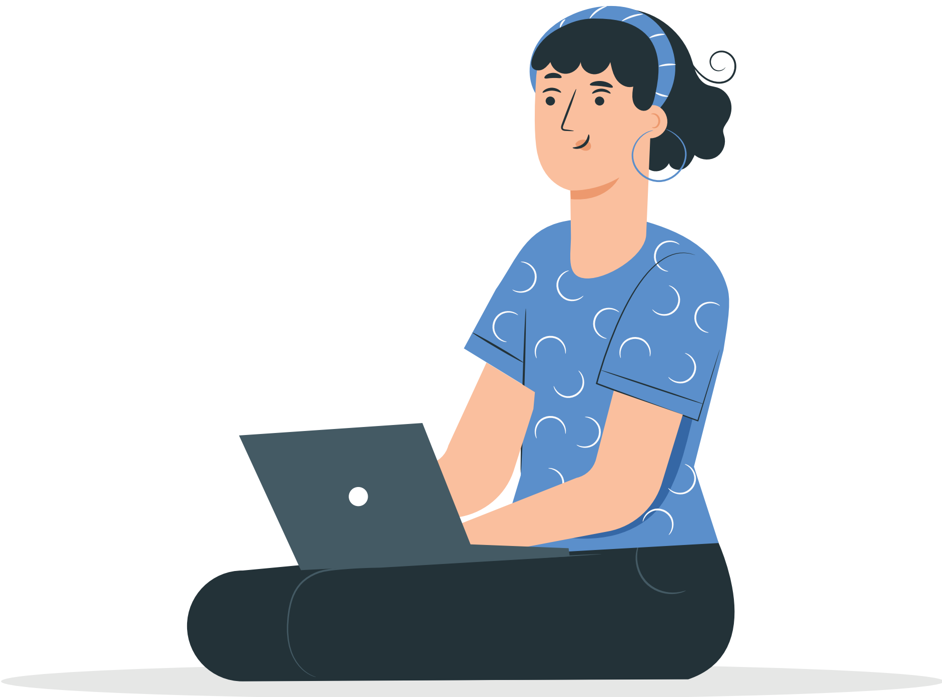
No matter how big or small an advocate's goal is, it needs to be put into a time frame. What do you hope to achieve with the advocacy in a month, year, or five years? Mapping out a time frame in a visual way will offer an idea of the current status and the future, so consider creating a physical timeline and keep it somewhere to sustain momentum, continue working toward your goals, and stay organized.

Establish goals and objectives (SMART) for establishing SMART goals includes timelines. Make sure the timelines are ambitious but also realistic; leave enough time for adverse scenarios so that changing direction while remaining on track is possible.

Advocacy Resources for an advocacy grant timeline sample which tracks funding activities. The same principle can be applied to other areas of your advocacy as well, such as event planning, marking an annual awareness day, or advocacy outreach

3.7. THE ADVOCATE'S STORY

Whatever the cause an advocate is working toward, it is important to condense the issues into a few concise lines or phrases. This will help advocates deliver an "elevator pitch" quickly to invested stakeholders. A template for creating a Personal Story is provided below.



ABOUT ME

Name
Street, City, State, Zip:
Phone:
Email:

- Name of agencies my family member works with:
- The challenges my family member faces:
- How their supports assist them on a daily/weekly basis:
- How staff turnover affects my family members and my family unit:
- How I see staff turnover/staff shortages affecting the employees:
- Without consistent and quality services her/his life would…
- …Our family life would be…
- Additional comments you want to make to your legislator about the importance of the Service Providers & Direct Support Professions that assist your loved one regularly:
- Without waivered community supports, my loved one's life would be impacted negatively in the following ways:
- Our family would be negatively impacted in the following ways…

4. COMMUNICATION IN ADVOCACY

4.1. WHY IS COMMUNICATION NEEDED?

Communication is an essential part of advocacy. Diverse activities such as educating patients and the public, policy work, and multi-stakeholder collaborations are forms of communication. Successful communication is a key ingredient that turns a good idea into successful advocacy.

4.2. DEVELOPING YOUR MESSAGE

Once a plan has been written down, go over it again to refine and tighten. Step away from it for a while; come back to it with a fresh mind to spot any weaknesses in the arguments or ask a colleague to look over what has been written. Others can be helpful sounding boards.

4.3. DESIGNING YOUR MESSAGE

4.3. A. DECIDE ON AN ANGLE

As an advocate, constantly connect with an audience and make the advocacy a part of their lives. Connections and relationships play a vital role in this regard as an audience must be interested in order to connect with you. How a message is delivered determines the personality of the advocate and how the audience connects with them, influencing people’s decision on whether they want to work with you.

There are multiple angles that one can adopt to deliver a message. However, one needs to understand the differences in perceptions and how these different perceptions influence one's relationship with stakeholders.

Advocates should ask themselves whether they are a victim, rebel, hero, monster, or an expert? These roles serve as the bases for building a message than can be shared. Which label is most appropriate or more appealing to your audience? The tone of the message will be chosen accordingly.

After selecting the angle of how you want to deliver your messages, start creating and spreading them.

4.3. B. START WITH THE AUDIENCE’S INTEREST

First, tell people the reason that would keep them interested in the content and why they need to pay attention to the message. This will capture their attention. We are often tempted to begin talking about ourselves, who we are and what we do; by the time we get to the core message, listeners have lost interest. Instead, always start with what is important for them.

4.3. C. TALK TO THE MIND, HEART, AND IMPULSE

People are different and react as such to arguments. Therefore, the following categories can be used in appealing to an audience to build an argument:

- Rational arguments - statistics, clinical trials results, experts' statements, etc.
- Emotional - personal or patient stories
- Conative - a call to action; here, clearly explain what you want them to do and why

Make it concise

People's attention span gets shorter every day. So try to be concise. Use a few words and depend on visual aids. Insert images and graphics, even short videos that express the message. At first, the message might seem too complex to express it concisely; eventually, you want your outcome to meet the core message. Everything else can wait!

Make it clear

Be sure that the language is simple enough that everyone can understand it, but elevated enough, proper, and complete so specialists also feel comfortable with the message. Always explain medical, legal, statistical, and other tough terms and ideas.

Make it simple

Avoid sending complicated messages or several messages at a time. Receivers will not understand what needs to be done first. Overwhelmed with all the ideas, they will probably lose track. When appropriate, use bullets for sending complex messages and emphasize the important words. The message will then be easy to read and understand.

Make it different

What makes you unique? How are you different from others that do the same thing as you? What makes your current message stand apart from the rest? Insert the answers within the messages, and people will notice them. People are bombarded by hundreds of messages from different organizations every day, so they tend to block or overlook them. Try to be different to capture their interest. Competitive advantage is what makes one different; in this context, the advantage is acquiring people's attention.

Make it yours

Use the same tone and language in all of the messaging. Use the logo, your name, and contacts, every time. People trust what they know; they know what they see repetitively. The message changes every time, but the logo, the organization's name, and sometimes the repetitive Template or Toolkit need to be consistent throughout so people become familiar them.

4.4. IDENTIFYING YOUR TARGET AUDIENCES

The target audience for advocacy is not the audience interested in this advocacy. These are groups of people we want to target as advocators.
By defining a target audience, advocates get to know them and can focus their strategy, tone, and content.

Patient Advocates tend to identify their target audience in order to deliver their message and reach their goals. This case demonstrated how the patient advocacy group "TTCF" in Tanzania identified their target audience “Members of the Parliament" and did evidence-based research about the hazards of tobacco production and use in order to be aligned with the "FCTC" and have effective control over tobacco products, and therefore, boost public health.

Advocacy report from Tanzania: Tobacco Control Forum (TTCF), Tanzania

An important advocacy program is the campaign targeting Tanzania's politicians and the community at large to foster the passage, adoption, and enforcement of the World Health Organization (WHO) Framework Convention on Tobacco Control (FCTC) compliant legislation. Tanzania has a Tobacco Products (Regulation) Act, 2003 (TPRA, 2003) which needs revision after the country ratified the WHO FCTC in April 2007. A review process was set up to ensure that the TPRA 2003 conforms to the WHO FCTC requirements. The Tanzania Tobacco Control Forum (TTCF) participated in this review process, which was conducted under the auspices of the Tanzanian Ministry of Health and Social Welfare (MHSW).

Unfortunately, the proposed bill addressing the modification of the TPRA 2003 has not been placed on the Tanzanian parliament's agenda. Due to this setback, TTCF made the decision to gather more evidence-based information on tobacco farming to be able to effectively fight the tobacco industry and convince parliamentarians of the hazards of tobacco and the need for adopting an effective tobacco control law. TTCF carried out tobacco impact surveys in the two major tobacco-growing areas in Tanzania, the Songea and Tabora Regions. The evidence gathered from the survey study was presented to Members of Parliament (MPs) from five parliamentary committees.

The MPs took the evidence very seriously and advised tobacco control advocates to prepare the draft of an FCTC compliant bill and present it to them for tabling to parliament. The MPs also advised that the collected evidence should be presented at a larger audience of MPs in order to gain more support.

With the support of the Legal Consortium of the Tobacco Free Kids Action Fund, TTCF has prepared the draft bill, which will be presented as a Private Members' Bill. The Bill was presented at the parliamentary session. TTCF planned to hold a bigger sensitization seminar for all MPs at the parliamentary session to facilitate the adoption of the proposed bill. The passage of an effective legislation will protect Tanzanians from tobacco smoke and therefore enhance public health.

In advocacy work, the two main audiences are usually decision-makers and influencers:

- **Decision-makers**
  They are the primary audience. Who are the individuals or groups who can take the decisions that need to be taken?

- **Influencers**
  They are the secondary audience.
  Which individuals or groups influence decision-makers?
  Being specific in identifying the audience makes communications more effective.
  Different audiences will be interested in different stages of awareness:
  Some will be ready to actively work on chronic disease prevention and control immediately, while others will require information about the issues first.
  Target them as individuals depending on your time and resources.

4. A. AUDIENCES AND STAKEHOLDERS

First, target audiences are not the same as stakeholders. Audiences are receivers of the message; a message is disseminated knowing that the only goal for the audience is to listen. Stakeholders are people or organizations that are impacted by the decisions or actions organizations make; stakeholders actively participate in building management reputation. The goal of this tool is to define who the message will be shared with in order to create awareness.

TARGET AUDIENCE

PURPOSE

A target audience is a specific group of people with shared interests, goal or characteristics who are most likely to be interested in your advocacy. By defining an target audience, advocates get to know them and can focus their strategy, tone, and the content of the message. This tool gives insight on who is the target audience and how to understand what they want.

WHAT IS A TARGET AUDIENCE?

First things first: your target audience is not the same as your stakeholders. Audiences are receivers of the message; you disseminate a message with the only goal for them to listen. Stakeholders are people or organizations that are impacted by the decisions or actions your organizations make, actively participating in your reputation management. The goal of this tool is to define to whom we will share our message to create awareness, not to balance their various interests.

IDENTIFY YOUR TARGET AUDIENCE

Define the challenge

Start with defining the challenge for your advocacy, or the problem that you want to solve. This gives insight in the people that suffer now and will benefit when this problem is solved.

Conduct research

Research websites and social media profiles from your competitors to sketch a picture of who you're talking to. Determine the scope of your target audience: is it broad (e.g., the global SMA community) or a niche market you're targeting (the French Duchenne families)?
To check if you have identified your target audience, you can answer the following questions:

- What is the problem you want to solve?
- Who is most likely to suffer from this problem?
- Who are my competitors?

ANALYZE YOUR TARGET AUDIENCE

To gain a deeper insight into your target audience's motivations and behaviors, an Empathy Map included the empathy map in section 2.3 can be used. The map can be used to analyze your target audience, and is originally created by Dave Gray. It can represent a group of users, just like a user persona can do. You can do this as an exercise in a group or create this during multiple conversations with your target audience, creating an overview of their needs and thoughts.

4.5. CHOOSE YOUR MESSENGERS

An avid advocate, who does not like public speaking and who wants to spread a message to a broad audience (i.e. reach out to people other than those in the community) can gather motivated people to collaborate and help with spreading the message. By having a clear goal, message, and tone of voice, one can delegate spokespeople and other influencers to effectively spread the message.

When picking the appropriate messenger, identify the people the target audience admires, respects, or looks up to. Sometimes, there is a need to ask a celebrity to endorse one's advocacy.

The case study below presents the impact of celebrities and influencers on spreading awareness about cancer. Furthermore, it shows how these celebrities and experts can help spread the message and fundraise for the advocacy groups.

A CASE STUDY ON PATIENT ADVOCACY/PARTNERSHIPS WITH EXPERTS AND CHAMPIONS

Employing experts and champions can be crucial in spreading the message of an advocacy program. Experts are people who provide an educated perspective on cancer. For instance, doctors and nurses with the appropriate experience can make excellent experts. Additionally, patients and their families can be very effective advocates – their experience is an invaluable reference for advocacy programs. Often, the explanation of a layman with experience of cancer can be both accessible and persuasive.

The People living with Cancer (PLWC) – South Africa have used celebrities to increase awareness of cancer in South Africa. Notable cancer survivors took part in the Cancer.vive fundraising motorcycle ride across South Africa. Janie du Plessis, a TV presenter and model, and Lilian Dube, a soap opera actress, took part in the ride. Cancer.vive generated significant media coverage on the internet and newspaper including 30 articles.

Several articles focused on the life stories of the celebrities, which will have increased awareness in a broad swath of society.

4.5. A. CHOOSING EFFECTIVE SPOKESPEOPLE

The person chosen to deliver a message is a key component in passing the message across. An effective spokesperson has good communication skills and can speak confidently to both groups of people and individuals. He/She should be able to concisely and accurately deliver a message. It is also important to make sure the message is being delivered in the right setting to the right people.

For example, if a spokesperson separately delivers a message to two competing bodies, he/she will need to adapt to the different audiences. This will allow him/her to get the message across effectively, gain respect, and avoid creating misunderstandings or conflicts.

Preserve the sense of trustworthiness by sticking to key facts and avoiding assumptions or outcomes that are not certain. Having the key messages in place will act as a guide indicating who should deliver the message, depending on its complexity, and who it should be delivered to. The spokesperson should be picked according to the message. A spokesperson should be involved in the advocacy work and should be invited to the related meetings and conferences. This involvement ensures that he/she is up-to-date since a message is always more convincing when the messenger knows the topic well, rather than working with a superficial level of knowledge.

4.5. B. COMMUNICATION WITH DECISION-MAKERS

Direct communication with decision-makers can be a very strong advocacy tool, and a great way to publicize the advocacy. Communication can take place through letters, telephone calls, emails, and social media. However, the ideal way to contact an influential decision-maker is through a face-to-face meeting. This might take a little longer to secure, but it's worth the extra effort.

Preparing some printed material laying out the advocacy is a good idea; it will help back up the key message and illustrate the ways the decision-maker can assist in delivering the message. It is likely that these people are pressed for time. Giving them breathing space will allow them to read the materials and understand the message at their own pace.

SAMPLE OF A POLITICAL LETTER

Dear XXXXXXXX.

Name
Address
Phone

Thank you for the political leadership you provide for our community. As a citizen who is concerned about the Earth's climate, I value the role you play in shaping the policies that can lead to greater sustainability for our city, our nation and our world. With the right incentives, policies that are good for the environment can also be good for creating jobs, improving our economy and lessening our dependence on foreign oil.

Our organization. Citizens Climate Lobby. is proposing such a policy. It works like this: Place a steadily-increasing fee on the carbon dioxide produced by fossil fuels and return all the revenue to every household. Increasing the cost of carbon creates a strong incentive to invest in clean energy. Returning the revenue from the carbon fee would shield households from the economic impact of rising energy costs. Eventually, the annual "carbon dividend- would be SI.500 a year for every person.

Unfortunately, our politicians in Washington are paralyzed with fear on this issue and unable to act. They fear the power and money of the big carbon lobby.
If I were them. frankly. I'd be afraid. too.

That's why we need the support of respected leaden like you. Your encouragement would help our members of Congress fmd the resolve to take the bold action that will lead our nation into the new era of clean energy. Our volunteers are taking this message to their senators and representatives, but your voice would make all the difference.

Enclosed is our legislative proposal. I will call you in hopes that I can meet with you in your office to discuss how we can work together to enact this legislation, which would reduce greenhouse gases and bring new jobs and cleaner air to our community.

Thank you for your consideration. Sincerely.

Name here. Citizens Climate Lobby

I believe the American people want climate policy to be transparent, honest, and effective... I firmly believe it is not too late for Congress to consider a carbon tax as the better policy approach.'

Rex Tillerson.
ExxonMobil CEO

We very much believe that a straightforward graduated tax on carbon is better than the cap-and-trade."

Fred Smith,
FedEx CEO

If politicians remain at loggerheads, citizens must lead.'

Dr. James Hansen, Physicist, Director of NASA Goddard Institute for Space Studies

LETTER SAMPLE

Tip: *Add personal touches whenever possible. For example, think about how have health centers, like Westside, have impacted you or your friends and loved ones one.*

[Date]
The Honorable **[Name]**
[Address]
[City], [State], [Zip Code]

Dear senator/Representative **[Name]**,

As your constituent and a member of the Board of Directors of Westside Family Healthcare, I am writing to urge you to vote for full funding for the Grant-In-Aid and Healthy Women, Healthy Babies programs.

Westside Family Healthcare provides high quality, affordable health care tower 28,000 Delawareans, regardless of their ability to pay. Our 6 sites and mobile health unit operate in underserved areas across the state, and many of our patients are uninsured or underinsured.

It is with the additional funding of Healthy Women, Healthy Babies that Westside is able to provide the best possible care to our patents. Despite the fact that Delaware has historically had a higher Infant mortality rate and pre-term birth rate, 95% of our prenatal patients delivered babies at a healthy weight.

I again ask you to support fug funding for state-supported health program such as Grant-In-Aid and Healthy Women, Healthy Babies, should questions their funding come up In this legislative session. I also encourage you to speak to your colleagues about doing the same. A healthier Delaware benefits us all.

Please contact me to let me know your position on funding for Gent-In-Aid and Healthy Women, Healthy Babies or with any questions you might have about the health centers in your district.
I can be reached at **[Contact Info]**.

Sincerely,

References & Resources

TALKING TO A POLITICIAN - FROM MOMENT TO MOVEMENT AND BEYOND - HOW TO WRITE A LETTER TO A POLITICIAN

Advocates should keep their message clear and concise. Bullet points are a good way to summarize information. Illustrations help because visual guides are often stronger and less time-consuming than reading through pages of information, which you might know well but the recipient will be trying to comprehend for the first time.

Before advocates talk to decision-makers, they should make sure that the message's short- and long-term strategy (using the Create a Strategy tool) is clear so that it can be efficiently delivered. Be well prepared for your appointment and trim down your message using the "Prepare a Pitch" approach.

If an advocate meets a decision-maker at an event and would like to leverage this meeting, they mention it on their social media streams and tag them in the posts. Nonetheless, using pictures from the encounter requires asking for permission beforehand to check if the decision-maker does not mind the picture being posted.

Ask when it would be okay to follow up on the meeting and the actions discussed. Whatever the reply is, follow up by email soon after the meeting to thank the decision-maker for her/his time and communicate why her/his involvement is meaningful.

PURPOSE

Whenever advocates plan for a face-to-face meeting, or just want to clearly and concisely explain what they do, a pitch is a great tool. A successful pitch is not just about presenting information and facts: It establishes an emotional connection.

To stick out in a crowd, it is necessary to prepare an eye-catching presentation with compelling messaging and a clear call to action. This tool is based on the AIDA-model (Attention, Interest, Desire, Action) and creates a clear structure on how to prepare accordingly and make a statement that sticks.

PREPARE YOUR MESSAGE

An effective preparation should answer the following questions:

- Who are you?
- What is your goal?
- What is the problem you are going to solve?
- Why is this needed?
- What will happen if you do not?
- How is this different than others in your field?

It should take the following elements into account:

- Presentation content
- Verbal communication
- Non-verbal communication

KEEP IT SHORT

A message that is short and sweet sticks the best. Cut additional superlatives and do not use jargon. The message should be understood by everyone.

STUDY THE AUDIENCE AND THE SITUATION

Each situation requires a different kind of focus. In general, a message can be the same, but prepare for a meeting by finding relevant stories to link to, emphasizing the urgency or need for a message.

START WITH A POWERFUL STATEMENT

A first impression can only be made once, so use it by making a statement that you will elaborate further down your conversation. You start by a key statement, a powerful one, precise and concise so it will retain a mental note for the reader and then you elaborate more later in the conversation

KEEP IT POSITIVE

Focus on the challenges at hand and how the solutions will be of benefit.

MAKE IT TANGIBLE

Create a deeper connection with the listener by stating why the problem should be solved and how this will result in a better world.

BE PASSIONATE

Be passionate, but not emotional. Show enthusiasm and engage the audience while staying professional and keeping excessive emotions at bay.

CALL TO ACTION

Finish a pitch with a clear call-to-action. This is an end statement designed to spark an immediate response from the audience. Be concise and ensure follow-up to keep the message at the top of their minds, and call or mail them later to continue the conversation.

References & Resources

CALL TO ACTION - 18 STEPS TO CREATE AND DELIVER A WIN - HOW TO PITCH A BRILLIANT IDEA - HOW TO PITCH B2B

4.6. TONE

Using the proper language in all the advocacy communications is very important. Patient advocacy is important and time-sensitive work. This may generate a sense of racing against the clock while trying to get people onboard to make the required changes.

Despite being pressed for time, advocates should avoid language that is provocative, confrontational, or inflammatory. Remain balanced and calm. Make your case by stating facts, which will allow you to remain credible and convince stakeholders, especially those who might be put off if they feel attacked.

Avoid vague language and wordiness. The objective is to get the message delivered as simply and as quickly as possible. If this can be done in five pages, there is no need to make the document twenty pages, for example.

Create a value document with adjectives that set the right tone in your communications. Is it emotional, encouraging and friendly, or rather inspiring, confident, and empowering?

4.7. IDENTIFY OPPORTUNITIES AND ACTIVITIES FOR MESSAGES

Use the following **Identify & Plan Opportunities** tool to uncover relevant topics, themes, and messages for the target audience by listening to stakeholders, making an inventory of competitors, and staying up-to-date on relevant developments in the field of interest. There needs to be enough examples and input to deliver relevant messages.

Subscribe to newsletters and **PubMed** articles; monitor the web by setting a **Google Alert** on interesting keywords; have casual or formal interviews with the target audience to reveal their needs and desires.

TOOLS & TEMPLATE: IDENTIFY & PLAN OPPORTUNITIES

PURPOSE

To be a successful advocate, you need to be continually innovating, and looking for opportunities to build a network. Identifying and creating new opportunities to carry out a strategy is essential for achieving an organization's goals.

This tool provides a framework for how to increase the efficiency of your organization. Use this tool in combination with the SWOT analysis tool (this can be found in section page ---) to uncover opportunities and validate your target audience.

IDENTIFY OPPORTUNITIES

Listen

The best way to learn is to listen, especially when it comes to mapping opportunities. What are their experiences on this? Their needs, wants, challenges, and frustrations? What have they tried doing, but failed? What have they liked or not? You can either do this via a formal interview, or an open conversation. Use the insights to further define the target audience's pains & gains.

Benchmark

Make an inventory of and analyze competitors' and fellow advocates' strategies. What are they doing (or not), and how do they do that? Analyzing competitors will help identify and develop opportunities to expand your reach.

Trends & insights

Subscribe to industry publications, join patient groups, keep a sharp eye on politics and governmental changes and set Google alerts for terms in your field of interest. In addition, follow other experts on social media. Immerse yourself and stay up-to-date on the latest news and developments.

PLAN OPPORTUNITIES

Enable resources

Map all available resources and implement them in an "opportunity plan." This can be either financial or human resources, or social capital in the form of trust and communications. Keep in mind that a little can go a long way, especially when it comes to resources. Actively participating on social media platforms, live streaming, events and conferences, mail to newspapers, and participating in radio and television programs are all relatively cost-effective techniques to enhance exposure. The same goes for inviting decision-makers or other influencers for a discussion or conference.

Lobbying & Negotiating

When advocates have chosen an issue, it is time to influence decision-makers and advance the topic by presenting a standpoint and debate with the opposition. Knowing who to address and how to do this is crucial. Lobbying can be done both formal (arranging a meeting) and informal (meeting them in the hallways or during events). Both require a high level of effort and expertise. Although an effective one, lobbying and negotiating opportunities can only be chosen if you acquire a deep knowledge of a target audience's motivation and needs.

Campaigning

By running a series of actions or events, you create momentum and word-of-mouth on a certain topic. The scale of this campaign can be anywhere between local and global, as long as you can leverage the right resources. Find fellow advocates and set up a campaign together, joining efforts. For more information about campaigning, see chapter "Campaigning Ideas."

Engage with the media

The media is essential when delivering an advocacy message to a broader audience. Engaging in social media is only one of the methods. Activities such as writing press releases, holding press conferences, and engaging journalists are effective ways to spread messages and create awareness.

CHECKLIST

- ○ **Interview stakeholders**
- ○ **Build up a network**
- ○ **Competitors research**
- ○ **Analyze different strategies**
- ○ **Subscribe to newsletters & Google Alerts**
- ○ **Scan through social media**
- ○ **Map existing, identify missing resources**
- ○ **Spread your message!**

References & Resources

DEVELOPING AND IMPLEMENTING THE ADVOCACY PLAN - IDENTIFYING ACTION STEPS

Subsequently, translate the findings into action by enabling resources that create leverage and influence decision-makers.

Choose the scale of the action and platform for wisely disseminating the message. Tapping into a different target audience means one needs to be prepared for both positive or negative reactions.

4.8. THE TARGET AUDIENCE AND WHERE TO FIND THEM

Think of who you are trying to reach:

- Other patients (organizations)
- Other patient advocates
- Pharmaceutical bodies
- Conference organizers
- Legislators
- Hospital staff
- Political figures

Good places to find a target audience:

- Medical conferences
- Patient conferences
- Patient bodies
- Advocacy events
- Local government meetings
- Online groups
- Social media platforms
- Traditional media connections
- Fundraising events
- Online webinars

Keep in mind that target groups vary in size and nature. Advocates should be prepared to tailor their message. When invited to speak at an event or receive a donation, carry out due diligence to find out who is organizing and sponsoring the event.

4.9. GETTING A MESSAGE ACROSS

- No matter how much you know about the disease you are advocating for, approach the audience as if they have not heard of it and avoid jargon.
- Limit written correspondence to a maximum of one page; people do not always have time to read long emails and letters.
- Begin with the most important points.
- Create an information kit that covers the basics of what you do, along with your contact details.

4.9. A. PRESENTING

- When presenting to an audience, speak clearly and use short sentences.
- Look at the audience and engage with them.
- If using slides, avoid cramming too much text onto one slide; it will be illegible at the back of the room.
- Keep the layout simple and do not use different fonts; your message should take center stage.
- Go into the presentation with more information than you will need so that you have material ready to answer questions.
- Practice in front of a mirror or present to friends who can time you and give you tips.
- Summarize your key message at the end of your speech.
- An image speaks more than a thousand words: Visuals help you convey the message that you want to spread and makes your presentation more appealing.

4.9. B. MEETINGS

- Networking is a crucial and indispensable part of advocacy. Learn to love it.
- If you are someone who finds approaching people you have never met and striking up a conversation difficult, a good tip is to pretend that the meeting you are at is your party, and all the attendees are your guests. Pretend to be checking up on whether your guests are having a good time at "your party," and this will make it a little easier to go for the initial approach. Keep your focus concise; if you have someone's attention for five minutes, focus on one issue rather than the six problems your patient community has.
- End meetings by exchanging contacts and requesting follow-ups.
- If possible, connect on Facebook or LinkedIn.

4.9. C. FOLLOWING UP

- Even the most eager contact can sometimes forget to respond. Send a gentle reminder after a few days.
- If you have a telephone contact, following up by phone is best and is more likely to get a result.
- Remind the contact about where and when you met and what you represent.
- Be wary of being persistent to the point of being annoying.

4.10. TRADITIONAL MEDIA AND HOW TO USE IT

For patient advocacy, raising the profile of a cause can be a great tool. Advocates are better off targeting their approach rather than trying to reach everyone. Select a few high-level outlets and proceed with building a relationship. Media outlets are broadcasting channels providing news, information, and feature stories to the public through newspapers, magazines, social media, and the Internet, television, and radio. Create useful and relevant content; using this content is the best way to reach out to the target audience on social media. Building a strong relationship with social media can be incredibly beneficial for advocacy.

Consider the following questions when contacting media outlets:

- How big is the outlet's influence?
- Who is the outlet's audience?
- How can you get connected to the outlet?
- How can you position yourself to fit into its content?
- If the response is positive, what is required of you in return?

Although it may feel like you have little control over the process of giving an interview or what a final article will look like, you have the right to know what kind of questions you will be asked. Rule out certain topics that you prefer not to answer. Ask to see the final article/media before it is released. Protect your hard work when approaching the media and be especially wary of being framed as a victim!

Some tips when working with the media include:

- Compile a media contact list and maintain it so that you are always addressing the right person.
- Be concise. Journalists are under pressure to choose and reject stories quickly.
- See if you can relate your advocacy to current events.
- Be upbeat. You should not appear to be a sob story.
- Pitches tend to be most successful in the middle of the week rather than at the start when readers are cleaning up their inboxes, or at the end when they are wrapping up their week.
- August tends to be a slow news month. If all else fails, pitch during this month.
- A little extra time to find out who to contact at an outlet pays off. A press release address with a name is likely to be more successful than sending a generic press release.
- Live TV may feel daunting, but it gives more control over how things go since it cannot later be edited to skew the debate in a certain direction.
- If you are still uncertain, consider enrolling in professional media training workshops that offer guidance.

PURPOSE

In this brief guide, we provide basic tips on how to write a newspaper cover story, links to additional resources on how to write a newspaper article, and a template.

WHAT IS A NEWSPAPER COVER STORY?

A newspaper cover story is the main/feature story that appears with a picture on the front cover of a newspaper or magazine. In the world of journalism, a feature story is an article that is not a news story. Feature stories are typically more original than news stories. For this reason, you rarely see the same feature story running in multiple media outlets.

Feature stories take more time to write than news stories and they are usually more creative, descriptive, and subjective. Whereas a news reporter will often quickly cover the “5 W’s of journalism”— who, what, where, when, and why of a story – a features reporter will cover those as well but will also delve into several long and nuanced variations of how and why, writing a much more extensive story that touches on concepts, ideas, impact, and cause and effect.

While they may have a tie-in to the news, feature stories do not usually cover something that happened in the last, say, 24 hours. A news story, on the other hand, covers something that is brand new, by definition.

In other words, a news story always covers events that happened recently. If a news story is written and it is not published relatively quickly, there is no point in publishing it; no media outlet likes to report "old" news that everybody already knows. In contrast, if a completed feature story does not run today, or even this week, it is not the end of the world because feature stories have a much longer shelf life than news stories.

PARTS OF A NEWSPAPER COVER STORY

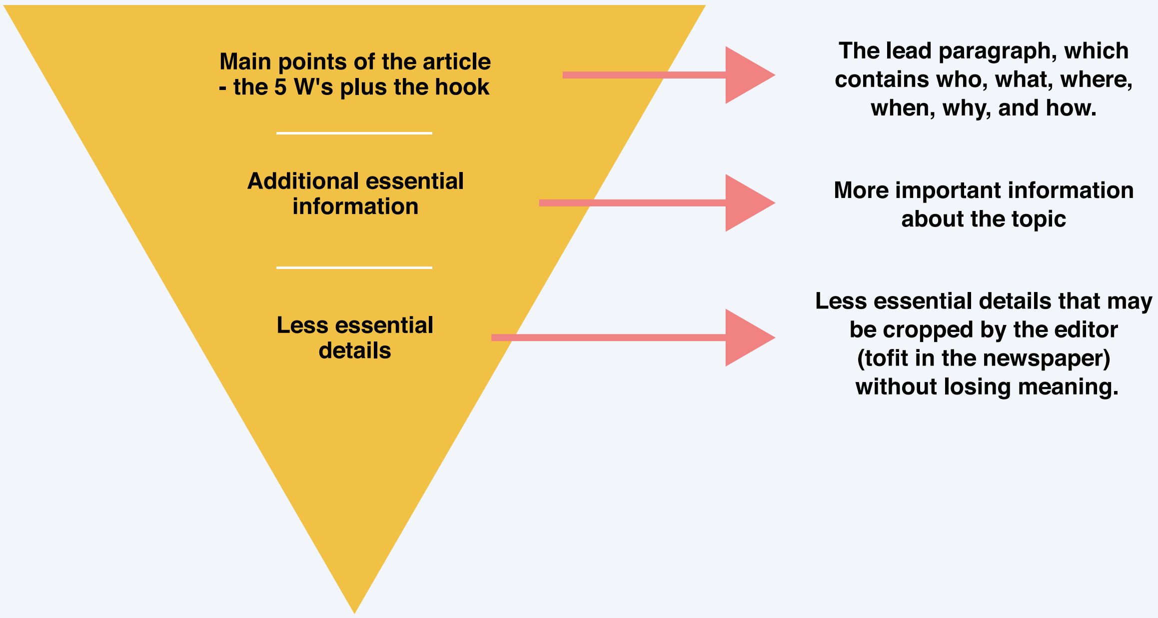
A newspaper article is usually constituted of five key parts:

- The headline is a short, attention-getting statement about the event.
- The byline tells who wrote the story.
- The lead paragraph contains the who, what, where, when, and why. Answers to these questions must be written in the opening sentences of the article and often provide the basis as to whether the reader continues with the rest of the story or not.
- The body/explanation comprises the relevant facts or details that the intended audience needs to know after reading the headline and lead paragraph. Depending on the context of the event, it could include direct quotes from the researchers, study participants, and/or community stakeholders.
- The additional information part contains those details that are of least importance. In other words, these are details that even if the editor opted to delete from the article, the author would not have to rewrite it to convey the intended meaning.

HOW TO WRITE A NEWSPAPER COVER STORY

- Compile a Fact list
  A fact list is an outline of all the pertinent facts and information that one needs to include in the article. Compiling a fact list is important to write a clean, succinct article and reduce chances of leaving out any relevant information about the topic or story.
- Use the inverted pyramid format
  It is advisable to use the inverted format. This means that the most important vital facts should be mentioned first, and the less important facts come later in the article. The first paragraph must be more important than the second paragraph and the second paragraph more important than the third, and so on.

INVERTED PYRAMID



References & Resources
INVERTED TRIANGLE

- **Check facts before concluding**
  Read over the article and provide support for all claims where necessary. Assertions need to be attributed to a source. Information that cannot be attributed to a reliable and appropriate source is not suitable for publication. Include names, dates, and contact information or address.

- **Remain unbiased**
  A news article is meant to convey direct facts, not the opinions of its writer. Keep writing unbiased and objective. Avoid any language that is overly positive or negative or statements that could be construed as support or criticism.

- **Concluding an article**
  Make sure your news article is complete and finished by giving it a good concluding sentence. This is often a restatement of the leading statement or a statement indicating potential future developments relating to the article topic.

- **Keep it simple**
  No big words! Newspapers are written for twelve-year-old reading level in order to accommodate readers of all backgrounds and abilities.

- **Every time is the first time**
  Provide background information. When writing about the latest in a series of events, do not assume precursory knowledge. Assume the reader is picking up the newspaper for the very first time, with no prior knowledge about a situation.

References and additional resources

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HOW TO LAND A FEATURE STORY PLACEMENT - HOW TO WRITE A GOOD NEWSPAPER ARTICLE - WRITE A NEWS ARTICLE

HOW TO WRITE A NEWS ARTICLE - FLEMING, GRACE. "HOW TO WRITE AN EFFECTIVE NEWS ARTICLE." THOUGHTCO

TOOLS & TEMPLATE: PRESS KIT

PURPOSE

With a press kit, or media kit, advocates enable influencers and other participants to easily share your message and engage with your audience. It provides content and information for reporters and journalists to quickly learn about your advocacy and goal and have access to visuals and other marketing material that they can easily implement. Whether you are talking to press or networking, a press kit is a useful tool to create a professional and validated look.

PRESS KIT ESSENTIALS

Digital press kits are commonly incorporated in websites and contain downloadable content to be distributed. Another way is to carry a digital press kit on a flash drive or USB, so you have easy access to it during conferences without having to download or upload large files on potentially unsteady internet connections.

YOUR STORY

This is part of your core strategy. Why are you doing what you do? Share your history, mission and vision, explain why you want to change the current situation, and why this is so desperately needed.

FACTS & FIGURES

Since when are you established? For how long have you been doing this? In what field are you operating, and with whom do you collaborate?

LARGE, HIGH-RESOLUTION IMAGES

Provide a professional, high-resolution picture of yourself, and provide additional pictures or graphics that help capture the core values of your advocacy. If you have a logo, make it easy for content publishers to use it by providing a high-resolution option in the kit. Make sure they have a compatible extension like .png, .jpg or .pdf and a transparent background to make it applicable for multiple backgrounds.

PEOPLE OF YOUR TEAM

Any additional people or volunteers that are part of your team can be listed here. Make sure their roles are listed, and provide a specific mail address to facilitate communication with audience, journalists, stakeholders, if possible.

PRESS RELEASES

If you already have press releases, incorporate them in your press kit or link to them, listed per date. This includes announcements, updates, partnerships, and collaborations.

SAMPLES OF ARTICLES/PRESS

Any previous articles that already have been published can be incorporated to give the reader an idea of who you are and what you do.

SOCIAL MEDIA CREDENTIALS

List the social media platforms you are active on, and if you have a well-established audience, highlight quantitative (number of followers, subscribers) and qualitative (comments, testimonials) data here.

ADDITIONAL

- Audio/video interviews
- Awards and recognition
- Involvements
- Social media audience
- Quotes
- FAQ's

KEEP IT UP-TO-DATE

Update your press kit whenever you have additional resources and ensure quotes and information are consistent and accurate.

References & Resources

9 THINGS THAT MUST BE IN YOUR ELECTRONIC PRESS KIT - HOW TO CREATE IMPACTFUL PRESS KITS - PRESS KIT MAKER

4.11. SOCIAL MEDIA

Due to its wide-reaching nature and easy access, social media can be a very important tool in advocacy. It allows advocates to promote causes and related events in real time and can also be a tool for making connections. The visual nature of social media can help lend a face to a cause, increasing engagement and empathy as well as raising the profile of the advocacy.
Social media can seem complex and daunting at first, but over time, learn the importance of developing and maintaining the skill of advocacy through social media and it will keep your advocacy on the radar of others, as well as allowing you to see what is going on in your arena of focus.

As with any other tool, there are pros as well as cons. Social media leaves the door open to anyone, and not everyone is likely to be friendly. Advocates can provide information if they think it is necessary, but they should avoid engaging in negative debates, especially heated arguments, which could leave a bad impression about them and their advocacy.

Advocates should plan messages in advance to maximize impact while keeping effort within perks. There are several (free) publishing tools that may help you pick the best time to post. In the social media template, you will find the necessary tools.

HOOTSUITE - TWEETDECK - CREATING SOCIAL MEDIA MESSAGES - PROVEN SOCIAL MEDIA ENGAGEMENT STRATEGIES

Conduct some research and follow important people and influencers in your field. Try to engage with them by tagging them into messages to spark a conversation.

Visuals and moving images gain the best attraction on all social media platforms. There are many Template or Toolkit websites to choose from to create basic banners, infographics, and posters to disseminate, like Canva.
With free video editing software, you can record and edit videos and create a professional look and feel.

Patient advocacy programs use different visual tools to provide education to patients. The following case study presents an example of how a PAG in Ghana spread educational material such as posters in order to create awareness about cancer and its associated factors to promote cancer prevention.

A CASE STUDY ON PATIENT ADVOCACY / EDUCATION ADVOCACY

Education of people who are unaware or unclear about the details of cancer is a valuable advocacy program as the beneficiaries of health education become proponents, supporters, advocates, volunteers, and agents of change. Posters and leaflets are common resources for spreading information. The resources should be developed with a target audience in mind. For instance, if you are looking to educate children, you should use language appropriate to that age group as well as plenty of color and pictures.

For a medical audience, you can use more technical language. You must also decide how to distribute the resources. If you are running awareness-raising events, resources can be given to attendees to ensure the message is heard. Posters can be placed in prominent spots to catch the eye of readers.

In 2011, the **AfrOx/ESMO/UICC** cancer posters were piloted in **Ghana**, in collaboration with the Ghana Health Service and NGOs. The aim of the pilot program in Ghana was to develop a template for a low-cost cancer awareness and prevention program that could be replicated in other developing countries.

The posters were officially launched in Ghana on World Cancer Day 2011, by AfrOx, ESMO, the Cancer Society of Ghana, and the Ghana Health service.

The Ghana Health Service (GHS) distributed the posters to health professionals across Ghana. In total, 17,250 AfrOx-ESMO posters were provided to the GHS, addressing smoking, exercise, fruit and vegetable intake, and cervical and breast cancer. The distribution of these posters was combined with the GHS cervical and breast cancer poster distribution, demonstrating a compatibility of the resource distribution with another national program.

Most of these resources will end up in health establishments, but the idea is that the general public visiting these places will also learn from the posters.

PURPOSE

Social media platforms have a low threshold for people to get to know you before actively engaging with your advocacy. It is the new word-of-mouth that builds your brand and gives them the opportunity to get to know you better at a pace they set themselves. In addition, it gives you an opportunity to engage with an audience, wherever they are in the world.

If you dedicate a few hours a week on social media sharing your story and what you believe in, you will build your brand at a relatively low cost compared to other forms of advertisement. It is the new press and television. Not to mention, it is (mostly) free!

IDENTIFY KEY STAKEHOLDERS

Start by defining your targeted individuals. Because after all, that is why you are using social media. Those people are your target audience, which is often divided into multiple segments.

If you want to identify your stakeholders, try to answer the following questions:

- Who can influence the way we operate?
- Who can impact/be impacted by our organization?
- Who can help us understand our issue/challenge?
- Who is interested in our success?

Now that you understand the scope of your key stakeholders, you boil them down to a few target groups or segments that have a high level of engagement and impact, so you know who you have to target for effective delivery of your organization’s core values.

Tip: Want to know more about your key stakeholders? Use the tool “Identify and Analyze Target Audience” and a tool called the Empathy Map to gain a deeper insight into the needs and desires.

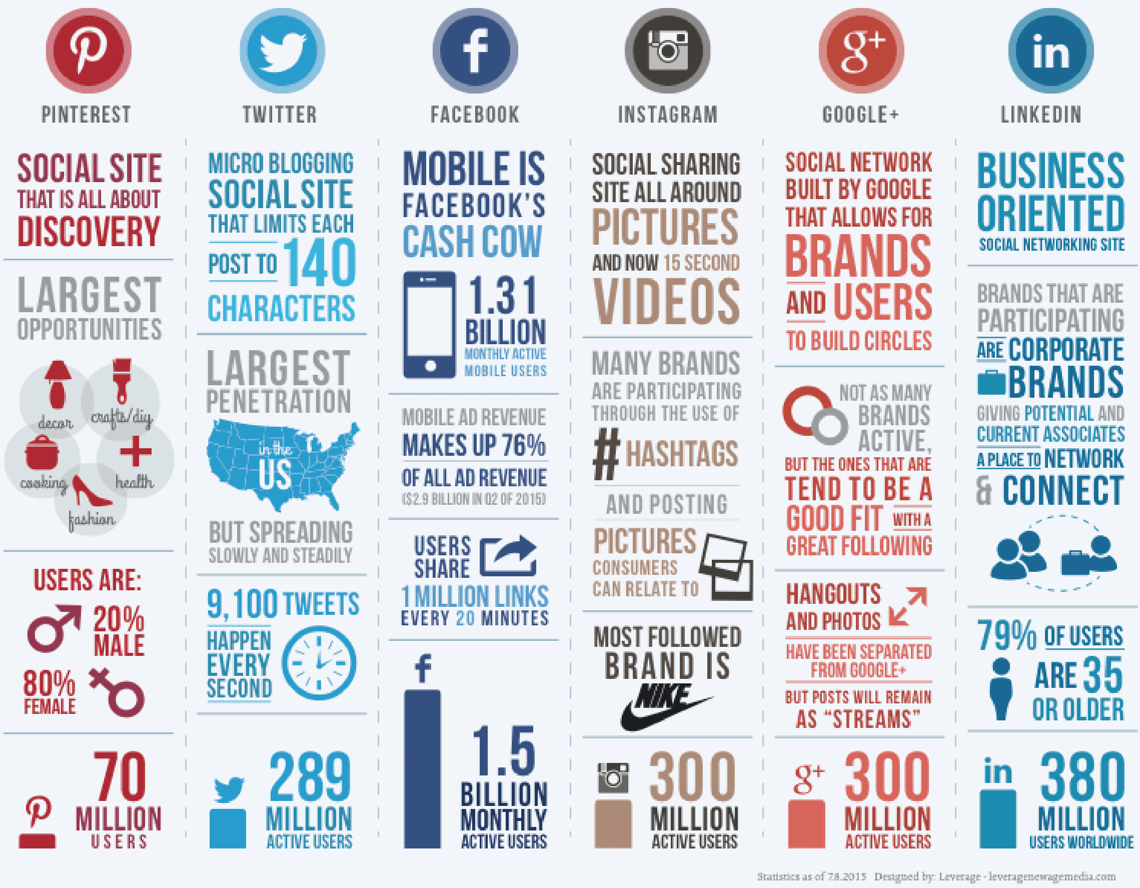
CHOOSE YOUR PLATFORMS

Then, you want to research the social media platform where you want to reach your audience. Each of those target group segments use different social media platforms. How do you find out which target group uses what social media platforms?

Dive into the demographics of the target audience. Are they male or female? Young or old? How much money do they make? Are they local, or from all over the world?

Once you know the audience a bit, you can use this information to discover which social platforms they use. Professional adults like clinicians over 35 make up the largest members of LinkedIn whereas Twitter and Facebook are primarily used by young adults. Teenagers and children tend to dive into YouTube and Snapchat.

Rule of thumb: Patients and caregivers are mostly active on Facebook and Twitter, whereas the industry, clinicians, and healthcare professionals are mostly on Twitter and LinkedIn. This distinction helps advocates craft key messages.



Reference

TOP 5 SOCIAL MEDIA PLATFORMS OF 2017

CRAFT KEY MESSAGES

You found your audience, but what are you going to tell them? Each stakeholder has a different intrinsic motivation to stay involved, so you each group within your network will need different messages and tones. For example, a patient can follow you on Facebook to find information about trials and get emotional support from the community whereas a clinician primarily checks your tweets to find out if there are interesting events to attend.

You always stay true to your mission or vision: the core belief of your organization.
Start with the basics: What do you want to tell them?

E.g.: "**We have all the information you need.**"

Then, you start refining your message, applying a technique called "wordsmithing." You can create messages that touches them, evokes emotion, and sometimes invite the reader to think deeper. Use active verbs to create motion, and explain what you want to reach:

E.g.: "**We keep you updated about the latest news and innovations around your rare condition.**"

Last, but not least, state how why you do what you do.

E.g. "**We collaborate with our team around the globe, making sure to keep you updated about the latest news and innovations around your rare condition, because we care for your health and wellbeing as a rare disease patient.**"

FORMULA: WE DO X SO THAT Y BECAUSE Z

Pro tip! If advocates are spreading the news in a language that is not their native one, it is always, always best to let a native speaker proofread the message. For example, when a Japanese designer presented new jumping shoes for the US market, he initially named them Spring up, Limber up, and Throw up.

TIPS & TRICKS

When advocates have crafted key messages, it is time to disseminate them via social media platforms. To make this social media part a little less time consuming, the following are some handy tips for time management.

- Interact with your audience
- Identify active users
- Use hashtags, measure what works (Google Trends)
- Share events and engage with other advocates
- Use emojis on Facebook and Twitter
- Include visuals, imagery, and video
- Share friendly links via Bitly
- Employ different language tones depending on the platform
- Publish at active times to increase impact
- Invite every post liker to like your page
- Focus on a campaign every month
- Smartphone first!

References & Resources

HOOTSUITE - TWEETDECK - CREATING SOCIAL MEDIA MESSAGES - PROVEN SOCIAL MEDIA ENGAGEMENT STRATEGIES

The following case study presents the patient advocacy role in raising awareness about the lack of health service coverage in Ghana using different social media tools. Their efforts were successful since they were able to deliver their concerns to the policy makers who initiated as a result some corrective measures

A CASE STUDY ON PATIENT ADVOCACY/RAISING AWARENESS ADVOCACY-WORKING WITH MEDIA

Ghana Parent Association for Childhood Cancer (GHAPACC) has been able to engage the media effectively. To increase awareness in the community, the association hosted a media event at the local international press center where many journalists are based. The secretariat of the press center advertised the talk to all resident media outlets. Many journalists were made aware of the association, without requiring them to leave their offices.

The media coverage gained has forced cancer advocacy to the forefront of the political agenda. After talking about the lack of health service coverage for cancer in Ghana on the radio, the Minister of Health was forced to publish a statement about coverage.

During a recent awareness raising event, media interest from several radio stations, newspapers and magazines (locally and internationally) was key to ensuring that the number of attendees was in excess of 500 people.

Media exposure is also capable of attracting sponsors. After hearing about the association on the radio, potential sponsors have contacted GHAPACC to discuss funding arrangements.

RESOURCES & REFERENCES FOR THE GUIDE

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Health Research Charities Ireland. (2019). *Evidence for advocacy: A practical guide; guidance on the generation and use of evidence in charity advocacy campaigns.* HRCI.
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WEBOGRAPHY FOR TOOLS AND TEMPLATES

1. PROJECT INITIATION DOCUMENT
2. PROJECT MANAGEMENT SKILLS
3.NEWPPM
4.CIRCLES OF INFLUENCE - INFLUENCE MAPPING
5.SMART GOALS
6.ESSENTIAL GUIDE WRITING SMART
7.SMART GOALS EXAMPLES
8.DEVELOPING AND IMPLEMENTING THE ADVOCACY PLAN
9.STRATEGIC - PLANNING-IDENTIFY ACTION STEPS
10.10 EASY RULES TO REDUCE RISKS ON PROJECTS
11.CALL TO ACTION
12.HOW TO PITCH -18 STEPS TO CREATE AND DELIVER A WIN
13.HOW TO PITCH A BRILLIANT IDEA
14.HOW TO PITCH B2B
15.HOW TO LAND A FEATURE STORY PLACEMENT
16.HOW TO WRITE A GOOD NEWSPAPER ARTICLE
17.WRITE A NEWS ARTICLE
18.HOW TO WRITE A NEWS ARTICLE
19.HOW TO WRITE A NEWSPAPER ARTICLE
20.HOW TO WRITE A NEWS ARTICLE
21.9 THINGS THAT MUST BE IN YOUR ELECTRONIC PRESS KIT
22.HOW TO CREATE IMPACTFUL PRESS KITS
23.PRESS KIT MAKER
24.HOOTSUITE
25.TWEETDECK - TWITTER
26.CREATING SOCIAL MEDIA MESSAGES
27.PROVEN SOCIAL MEDIA ENGAGEMENT STRATEGIES