

Toolkit on Empowering Leadership and Positive Governance



September 2019

Author: Lachezar Afrikanov, Your Ideas Matter LTD **Contributors:** Aleksander Evtimov, Victoria Behar, Rozalina Geneva and Veneta Kuyova, Your Ideas Matter LTD

Edited by Elena Balestra European Patient Forum

CONTENTS

INTRODUCTION	4
CHAPTER 1 - NEW PARADIGMS OF LEADERSHIP	5
Current Leadership Challenges Discovering the concept of Learning Organisations Lessons from EPF's Leadership Programme Main Principles of Effective Leadership in practice	5 6 6
CHAPTER 2 - DEVELOPING YOUR LEADERSHIP STYLE	8
Understanding mental models Tool 1: Helicopter view Tool 2: Iceberg Acknowledging Different Perspectives Tool 3: Intentional observation Empathising with People Tool 4: Empathy map Tool 5: Daily gratitude Presencing	8 8 9 10 1 12 13 14
CHAPTER 3 - EMBEDDING POSITIVE GOVERNANCE	15
Leading by example Tool 6: Leadership Compass Setting A Positive Atmosphere Tool 7: Walking talks Tool 8: Thank you briefs Co-designing and Implementing Decisions Tool 9: Advice process Tool 10: Coaching circles Tool 11: Design thinking Reigniting the Board Tool 12: Board members induction guidelines Keeping up with Members Reconnecting with Volunteers CHAPTER 4 - DEVELOPING YOUR EXTERNAL COMMUNICATION	15 16 16 17 18 18 19 20 22 23 24 24
Seeing Points of Impact	
Tool 13: Behaviour over time graph Recognising Organisational Value Co-creating Solutions	27 27 27 28
TEN RULES OF QUALITY LEADERSHIP	29
REFERENCES	30

INTRODUCTION

The current toolkit aims at strengthening patient organisations by enhancing the leaders' leadership skills, consequently enabling positive governance in their daily work. EPF's overall objective is to support patient organisations in positioning themselves as legitimate stakeholders, strong advocates and reliable partners in national and European health policy.

This publication is a synthesis of knowledge and expertise, based on modern global leadership paradigms and lessons learnt from EPF's 2018 Capacity Building Module on Empowering Leadership and Positive Organisational Governance, which engaged 24 patient organisations leaders from 16 European countries.

The toolkit aims to provide comprehensive guidelines and instruments to leaders of patient organisations, structured in five chapters as follows:

- Chapter I focuses on current global trends in organisational development and main principles of effective leadership of a patient organisation;
- Chapter 2 aims at developing a leader's own leadership style;
- Chapter 3 highlights key steps to embedding positive governance in the organisation;
- Chapter 4 is centred on the leader's communication with external environment.

The toolkit is designed to be a pool of resources to be used on other occasions as well as a selflearning manual.

"The number one leadership challenge in the world of business, government and civil society is the same. It is to enable stakeholders' groups that need each other to change the system to move from ME to WE – that is, from ego-system awareness to eco-system awareness."

Otto Scharmer, 2018



1. NEW PARADIGMS OF LEADERSHIP

Current Leadership Challenges

Today, we are living unprecedented times. The advancement of technology has achieved a great deal in many fields of socio-economic development. Modern organisations operate amidst volatility, uncertainty, complexity, chaos and ambiguity.

Patient organisations are not immune to the challenging environment we are all living in and are possibly even more concerned.

Patient organisations and their leaders are becoming more and more visible actors in the healthcare arena. This is an important and positive change. Nevertheless, new challenges are emerging!:

- Daily workload is on the increase and is adding pressure on leaders in terms of time management and ability to strategize;
- Lack of effective fundraising mechanisms to ensure that the organisation's activities and expansion plans are secured with financial resources with a sustainable perspective;
- Lack of expertise of staff members;
- Difficulties in finding volunteers;
- Fluctuating levels of engagement of staff, board members and volunteers;
- Lack of public recognition (the scope and roles of patient organisations are still very often misunderstood).²

Discovering the concept of Learning Organisations

A possible way to create the change we need and allowing our organisation to surf across times of change is to explore the concept of **learning organisations**. Learning organisations are entities that can adapt to the constantly changing environment and turbulent dynamics. To achieve the status of learning organisations, one of the world renown experts in systems thinking, Peter Senge postulates in his seminal book "The Fifth Discipline" that organisations and their leaders should adopt five disciplines of learning:

- Personal mastery is related to the leader's and every staff member's motivation to continuously improve one's competences.
- 2. Mental models is related to developing awareness of one's own and others' attitudes and perceptions.
- **3. Shared visioning** is focussed on the importance of having a common purpose within the organisation.
- **4. Team learning** is focussed on the importance of ensuring effective interaction within the organisation.
- 5. Systems thinking is related to understanding interdependency in the world. By promoting this type of capacity, leaders recognise and manage complexity and achieve constructive change.³

¹ The list of challenges presented is a synthesis of observations from the 2018 EPF capacity-building programme for patient organisations in the field of leadership and governance.

² Driving Better Health for Patients in Europe, EPF 2017 Annual Report, http://www.eu-patient.eu/library/Annual-Reports111/
3 A public speech on Systems thinking, delivered by Peter Senge, 2014, https://www.youtube.com/watch?v=0QtQqZ6Q5-0

The concept of learning organisations and the five learning disciplines for organisational leaders to embrace has been further developed by Otto Scharmer⁴, who invites organisational leaders to embrace a 7-phase solution making process, also called Theory U, to operate effectively in the current reality. The first four phases can be defined as the personal transformational journey of the leader to hone her/his capacity for sensing future developments, and then come up with sustainable solutions.

Leaders who manage to complete their inner journey are equipped with the right mindset and attitude to oversee the direction for future development (vision) and formulate an intention for the organisation's development. Following this, they can enter into a collaborative process with their team and move from enacting a vision and intention into co-designing a prototype of a possible solution. The final stage will be to embody the designed solution and implement it in the daily activities of the organisation.

Lessons from EPF's Leadership **Programme**

EPF promotes several key values and approaches, which contribute to shaping strong and successful patient organisations:

- Transparency is the obligation or willingness of organisations to publish and to make relevant data available to stakeholders and the general public.⁵
- **Accountability** is the willingness of an organisation to account for its activities, accept responsibility for them, and to disclose the results in a transparent manner.
- **Democracy** stipulates that patient organisations have governing bodies,

- which are elected by their members, who are patients, their carers, or their elected representatives.
- **Empowering Leadership** relates to the process of co-leading with team members (either paid staff or volunteers) and board members so that they can take initiative and make decisions to solve problems and improve services and performance of the organisation.
- Positive Governance relates to the process of making and implementing decisions. It is not about making "correct" decisions, but about designing the best possible process for making decisions.

The present model was developed by patient organisations' leaders, taking part in the 2018 EPF capacity-building programme in the field of empowering leadership and positive governance.

Main Principles of Effective Leadership in practice

- The key starting point in achieving effective leadership is adopting a set of fundamental principles to serve as guidelines for leader's behaviour. The characteristics of a good leader identified by EPF 2018 Capacity Building Module participants, the concept of learning organisations and the 7-phase process of Otto Scharmer are all based on 3 main principles:
- **Lifelong learning** by accepting that leadership is a process of continuous selfmastery, the leader remains open and flexible to new situations and unexpected circumstances. Furthermore, embracing the idea that learning is a never-ending process would allow changing the attitude towards unsuccessful undertakings and developments. Lifelong learning activates positive attitude, creative thinking and courage to experiment.

⁴ More information about Otto Scharmer and Theory U can be accessed at: http://www.ottoscharmer.com/5 EPF Fundraising Toolkit 2016, http://www.eu-patient.eu/library/toolkits/

The main characteristics of the successful leader of a patient organisation can be visualised with the following graphic:



- Understanding multiple perspectives by accepting and acknowledging that every person brings a new perspective to an issue at hand, the leader creates an atmosphere for collaborative dialogue and motivation for high staff performance. Seeing one situation through the "eyes" of different participants in it prevents the leader from being stuck in one's blind spots and taking ineffective actions.
- Co-creating decisions by accepting that the best decisions are taken collectively, the leader fosters a sense of ownership across organisational team, the board, members and volunteers.

We invite you to further explore these principles by implementing the steps proposed in the next chapters of the toolkit.

2. DEVELOPING YOUR LEADERSHIP STYLE

In this chapter, we invite you to take on a journey to establish a new leadership style, which will enable you to be more sensitive to emerging future trends and maintain a strong strategic focus. The journey has four distinctive milestones⁶:

- 1. Understanding Mental Models;
- 2. Acknowledging different perspectives;
- 3. Empathising with People;
- 4. Presencing.

Understanding mental models

Human behaviour is based on patterns that are usually rooted in subconscious mental models. In other words, we believe that we know what triggers specific actions, but there is a deeper source driving us to act in a certain way or another, or not to act at all. In the past, this modus operandi contributed to our survival and to transferring our legacy to the next generations.

In modern times of interdependency and fast speed of events, our mental models might not always be able to provide us with a clear picture of what is right or wrong, good or bad, positive or negative. They tend to keep us in our comfort zone, which prevents from expanding our horizons.

One example of a mental model might be: "We are patient organisations. As patient organisations we can look for funding **only** from donors and funding programmes in the health sector". While the statement sounds valid, it can be questioned by the fact that there are many other donors outside the health sector, which can be interested in supporting patient organisations

as representatives of different target groups like young people, employed, civil society. The mental model "we can get funding only from the health sectors" might confine us from exploring other possible sources.

Recognising mental models is a challenging task, requiring continuous self-evaluation. You can use two tools to foster your skills of self-evaluation – Helicopter view (Tool 1) and Iceberg (Tool 2). These tools will help you build a self-evaluation habit, which will gradually lead you to understand that several of your mental models are stereotypes and limiting beliefs, which are restraining your leadership and consequently your organisational development.

Tool 1: Helicopter view

The Helicopter view allows you to make a regular audit of your journey and map mental models (restrictions) that are preventing you from expanding your full potential.

What do you need for the exercise?

- A quiet and comfortable place;
- A notebook and a pen.

How much time do you need for the exercise?

You can try having self-evaluation sessions once a month for 30 minutes.

Instructions:

Before starting the exercise, please take a 5-minute break, trying not to think about anything or if thoughts are coming observe them without

⁶ The proposed journey is based on Theory U of Otto Scharmer.

judgement. Observe whether you feel tension in some parts of your body and just focus your attention gently to the tense areas and breathe.

Then once your mind is clear, proceed with replying to the following sequence of questions looking at yourself from the outside as if you were another person⁷:

- What are the 3 or 4 most important challenges or tasks that your life (work and non-work) currently presents?
- 2. What frustrates you the most about your current work and/or personal life?
- 3. What is holding you back? Describe 2 or 3 recent situations (in your work or personal life) where you noticed one of the following three voices, which prevented you from exploring the situation more deeply: voice of judgment; voice of distrust; voice of fear.
- 4. Watch yourself from above (as if from a helicopter). What are you doing? What are you trying to achieve at this stage of your professional and personal journey?
- 5. Imagine you could fast-forward to the very last moments of your life. Now look back on your life journey. What footprint do you want to leave behind on the planet? What would you want to be remembered for by the people who live on after you?
- 6. From that (future) place, look back at your current situation as if you were looking at a different person. Now try to empathise with and help that other person from the viewpoint of your future self. What advice would you give to that person?
- 7. Now return to the present and crystallize what you want to create. What vision and intention do you have for yourself and your work? What

- are some essential core elements of the future that you want to create in your personal, professional, and social life? Describe the images and elements that occur to you as concretely as possible.
- 8. What would you have to let go of to bring your vision into reality? What is the old stuff that must die? What is the old skin (behaviours, thought processes, etc.) that you need to throw away?
- 9. Who can help you make your vision a reality? Who might be your core helpers and partners?
- 10. If you were to take on the project of bringing your intention into reality, what practical first steps would you take over the next 3 to 4 days?

Tool 2: Iceberg

The lceberg tool allows you to understand your mental models in a concrete event/situation. For the process to work, think of a recent or current difficult situation in your organisation (e.g., a key staff member leaves, a key donor refuses to provide you with the needed funding, a group of patients is complaining about your recent initiative, the volunteers are extremely passive in their work).

What do you need for the exercise?

- A quiet and comfortable place;
- A notebook and a pen.

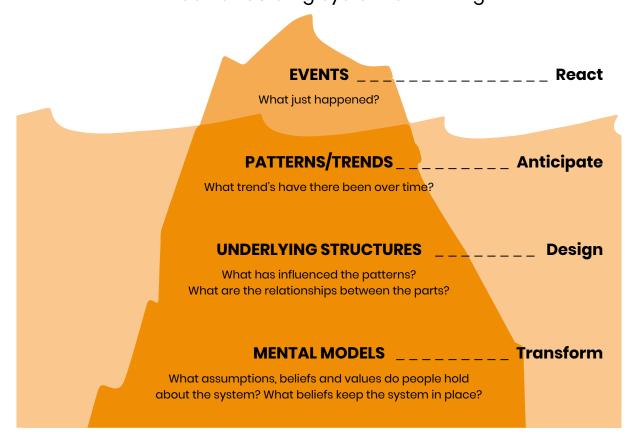
How much time do you need for the exercise?

You will need 40-60 minutes to complete the leeberg process.

⁷ The current list of questions is adapted from a practice called "Guided Journaling". For more information, you can check it here: https://www.presencing.org/#/resource/tools/guided-journaling-desc

THE ICEBERG

A Tool for Guiding Systemic Thinking



Instructions:

- Event / Situation What has just happened?
 (e.g., a key staff member leaves);
- Trend related to the Situation Think of similar situations in the past. Do you find any common factor that influences these situations? (e.g., key staff members leave when work pressure gets higher than usual);
- Underlying structures What is influencing the trend? (e.g. the work pressure is caused by private donors' demand for high results with short notice);
- Mental models What are your assumptions, beliefs and values that keep you in this place? (e.g. "I cannot ask too much from volunteers, since they are not paid staff");

8 For more information on Iceberg model, https://nwei.org/iceberg/

You can also print or sketch and use the graphical version⁸ of the Iceberg tool:

Acknowledging Different Perspectives

The emerging paradigm of leadership requires being open to acknowledging different views, coming from both staff members and stakeholders. Mapping alternative ideas is the source of organisational innovation and sustainable team engagement.

There is not a "recipe" for doing this. One possible route might be to foster one's attention on differences. It is important to highlight that at this point you are not asked to accept different opinions, but merely acknowledge their existence. Charles Darwin used to make a note of all counterarguments to his famous theory in his notebook, concluding

that although he was not feeling comfortable with these arguments, they might contain seeds of next discoveries.

Try to pay attention on your listening. If you catch yourself having thoughts along the lines of "I know this stuff. Nothing new for me," while listening to another person, this might be an indication that you are not actually listening, but you are confirming your own past knowledge on a certain issue. In such case, try to suspend this type of thinking and focus on those elements in the person's speech that are most surprising, most unexpected or most interesting to you.

The process of purposeful spotting of differences might not always be pleasant. In most cases it is frustrating, because the ideas you hear will probably be in direct opposition with your understanding of where and how the organisation should go on. One way to alleviate the effect from negative emotions is to practice **Intentional observation (Tool 3)**.

Tool 3: Intentional observation

The intentional observation exercise enables you to adopt an outsider perspective on events, circumstances and activities and thus prevents you from feeling stressed and frustrated.

What do you need for the exercise?

A clear mind.

How much time do you need for the exercise?

When you start practicing intentional observation, allocate a concrete time for the activity (e.g., 15 minutes per day). Define how this time will be distributed: at the start/end of the working day, during staff meetings, dispersed across the whole day, etc. Try to experiment with all possible combinations. After some days of practice,

gradually start increasing the time for observation, until you reach a moment when you feel you do not need to allocate any more time to observation, as it will have become a natural habit.

Instructions:

During the intentional observation exercise, try and gather your thoughts, feelings and body sensations without judging them. The key to achieving this is by focussing on the here and now.

Some examples of intentional observation exercises:

- Walking on the street: Usually, when we walk to work we think of so many things that we forget that we are walking. Try and feel every single step you make. Focus on your feet and the synchronization of your legs in this process. Keeping this focus, try to expand it by paying attention to every detail in the environment during your walk houses, cars, trees, flowers, animals, and other pedestrians that you pass by. You can experiment with the same technique, while you are driving or cycling to work.
- While eating: Usually, when we eat, we are
 preoccupied with other matters. Try to eat
 while focusing on the food. Try to imagine the
 whole process of how it was prepared for you
 and all the tastes that it brings. Enjoy!
- Sitting at your desk: While working at your computer, try to slow down a bit: feel your feet on the ground, then shift upwards and feel your hips on the chair, then your elbows placed on the desk, till you reach your fingertips touching each button on the keyboard.
- During a work meeting: You are having an intense discussion. Try to slow down and lay back on your chair for a while or if you are standing, take a comfortable position. Breathe in. Breathe out.

• Watching your thoughts and emotions appear and then fade away acts as a reminder that you are not your thoughts and emotions. They can be very powerful, and may carry you away with them, but they are just things that happen. You may fight against them or try to hold onto them, but in the intentional observation exercise you will simply let them be, allowing them to act, as they will, and perhaps notice what happens when you do this.

Empathising with People

The next step in the journey is to adopt the appreciative inquiry approach to your interactions with other people. In acknowledging different perspectives, the focus has been on identifying and recognizing different views that might exist on a given issue. At this point you start developing your capacity for empathy, you develop appreciation for the person and the ability to accept this person's authenticity. Embedding empathy in your leadership style will enable you to better connect with people.

It is easy to empathise with those who are from your community of like-minded people. What about others? What about persons from "extreme groups"? What about people that you fear, or you feel are absolutely disconnected from you? These people can be a valuable source of information for sustainable and positive solutions.

Our courage to reach out to these groups and try to walk in their "shoes" is the key to successful projects and initiatives. It is probably unrealistic to develop full empathy for them, but it is important to try looking beyond the evident and finding something that truly interests you about that specific group, something that sparks your appreciation for them.

You can use two exercises to foster the ability to empathise with people – Empathy map (Tool 4) and Daily gratitude (Tool 5).

Tool 4: Empathy map

The empathy map is part of the design thinking tools, allowing you to get a deeper understanding of a given person.

What do you need for the exercise?

- A quiet and comfortable place;
- A notebook and a pen.

How much time do you need for the exercise?

You will need 1-2 hours, depending on the information you have in advance for the person you will focus on.

Instructions:

Designing an empathy map takes time, so it will be recommended to depict a person that is important for you and your organisation, for example it can be a team member that you are having trouble motivating, or a policy-maker that is standing in front of a desired patient-related reform. It can also be a board member, who whatever you do is silently critical to your proposals.

When filling an empathy map you can use the proposed template with guiding questions⁹ below, or search for an online version that suits your needs.

The information you will collect using the Empathy map will allow you to see the given person from a holistic perspective and find possible points where you can engage in effective interaction.

 $^{9 \}quad \text{The current template proposed is developed on the basis of templates of Design Thinkers Academy, https://www.designthinkersacademy.com/\\$

EMPATHY MAP

PERSON:

- Provide a quick sketch/drawing of the person
- Name and Age

IDENTITY:

- Who is the person?
- What are his/her main characteristics?

BEHAVIOUR:

- What is this person doing typically on a daily basis?
- How does one day of this person look like?

ATTITUDE (VALUES):

- What is his/her general attitude towards things?
- What is his/her general attitude towards the issue at hand?

PERSONAL GOALS:

• What are his/her personal goals?

QUOTES:

• What are his/her most typical statements and or sayings?

Tool 5: Daily gratitude

In general, we express gratitude for something concrete, for example when saying, "Thank you for sending me this file! Thank you for calling me back!" While this is valid, we would like to invite you to turn gratitude into an ongoing characteristic of your behaviour and state of being.¹⁰

What do you need for the exercise?

• An open state of mind.

How much time do you need for the exercise?

This is an ongoing activity. The individual gratitude moments can take from a few seconds to 1-5 minutes, depending on the concrete situation.

10 This exercise was inspired by Rhonda Byrne (The Secret), https://www.rhondabyrne.com/

Instructions:

The simplest technique is to try starting and ending your day with gratitude. In the morning, the first thing we invite you to do is to think of the important things you need to do during the day and just be grateful for their successful implementation. In the evening, before going to bed look back and say thank you for the experiences you had.

Continuing to practice gratitude every morning and evening, you can try to expand this exercise to all daily activities. Take a special look at activities and experiences you usually take for granted and just mentally be thankful for their contribution to your life.

Some people might doubt the notion that by thinking "I am grateful for..." you can activate the positive energy of gratitude. What you could do is try when expressing gratitude to place one or both hands on the area of your heart and sense what feelings will emerge.

Eventually, you can expand your practice to focusing your gratitude on people and organisations you interact with and observe how your new attitude will start transforming their attitude, as well.

Presencing

"Presencing" is a term coined by Otto Scharmer to emphasise the importance of developing the skill of being present here and now, when taking decisions for the future. During this step, we invite you to operate from a here and now perspective. Being present in the very moment enables you to use your leadership capabilities to their full extent. This state of being is individual for every person. For some people, when being present here and now, i.e. "presencing", when people are living in

the here and now focusing on what they are doing in the moment - meaning being in a presencing operating mode, they feel relaxed and having a Meta perspective on a given situation. For others, there is an intense flow of creativity and joy. For others, it is about feeling comfortable to be in silence.

In all cases, it is important to highlight that to achieve a "presencing state" of being you need to pay attention to two dimensions:

- Past <-> Future. If you catch yourself having thoughts and concerns about past events and situations, you are not in the present moment.
 Similarly, if you are always thinking about the future this shifts your attention from the things that are happening right now.
- I < -> They. If you feel much engaged with your personality and its role in all processes or with the role of other persons, for things not to be happening in the right way for you, this creates a tension that holds you back from being in the here and now.

Here and now presence is a state during which you do not feel judgmental, but open to a deeper wisdom that is everywhere around you. A strong metaphor for here and now, presence is the feeling of being transparent.

Practicing presencing is a challenging task for organisational leaders. In practical terms, the exercise of presencing is recommended for moments of strategic planning, when leaders need to have all their senses, including intuition, working at their optimal level. This is the right state for you to formulate a global intention for the future of the organisation, which you will further co-design and put into a vision together with your board and members.

[&]quot;Presencing" is a term coined by Otto Scharmer to emphasise on the importance of developing the skill of being present here and now, when taking decisions for the future. Mr. Scharmer created the Presencing Institute, which is dedicated to promoting this concept. For more information: https:// www.presencing.org/

3 EMBEDDING POSITIVE GOVERNANCE

In this chapter, we invite you to adopt positive governance as a key characteristic of your organisation. There are several dimensions to consider while introducing the concept of positive governance in your organisation, such as:

- Leading by example;
- Setting a positive atmosphere of work;
- Co-designing and implementing decisions;
- Reigniting the board and reconnecting with volunteers.¹²

Leading by example

As highlighted above, empowering leadership opens space for positive governance. The first step is to check to what extent you possess main leadership values, such as trust, competency, consistency and commitment. When you adopt a new style of behaviour, it starts to "charge" the organisation with new energy. Along with creating your mental models, you should acknowledge different perspectives, learn to empathize with people and attempt to reach a "presencing state of being" through the practices described in the previous chapters.

Keeping ongoing focus on your behaviour in alignment with positive governance values is the first most important condition to achieve sustainable results in creating a new organisational culture or nurturing the already existing positive one.

You can use the **Leadership Compass (Tool 6)** to sustain your leading by example intention.

Tool 6: Leadership Compass

Usually, it is easy to commit to a certain type of leadership behaviour, but the real challenge comes when you need to turn this behaviour into a sustained habit. Leadership Compass invites you to allocate a specific time during your work day for self-reflection on the extent to which you manage to embed *leading by example* on a daily basis. The tool supports leaders in two directions: 1. To acknowledge their progress in leading by example.

2. To map areas for improvement.

What do you need for the exercise?

- A quiet and comfortable place;
- A notebook and a pen.

How much time do you need for the exercise?

About 7 minutes, at the end of each work day.

Instructions:

Before starting the exercise, please take a 2-minute break, trying not to think about anything or if thoughts are coming observe them without judgement. Observe whether you feel tension in some parts of your body and just focus your attention gently to the tense areas and breathe.

Once your mind is clear, proceed with writing down the replies to the following questions:

 How do I project trust to my staff, volunteers and board members?

¹² The proposed steps are based on Theory U of Otto Scharmer, Reinventing Organisations of Frederic Laloux and insights from leaders of patient organisations that participated in the 2018 EPF's capacity building programme in empowered leadership and positive governance.

- To what extent am I delivering successful NGO management?
- To what extent am I consistent in my actions and attitudes towards people?
- To what extent do I demonstrate dedication for the work processes in the organisation?

Read through your replies and see what are the learnings that you can integrate in your leadership style. Try to repeat the exercise every day.

Setting a Positive Atmosphere

The quality of organisational climate is determined by the quality of relationships you will create and maintain with your team members meaning staff, volunteers and board members.

The starting point in the process of nurturing positive atmosphere in the organisation is ensuring clarity of vision, goals and responsibilities. This step is the mutual agreement between you and other people involved in the organisation.

Along with the introduction to formal documents like the organisation's statutes and occupational descriptions, it would be recommended to have individual talks with each person in the organisation. These initial talks will help you overcome potential differences between visions and goals of team members. Ensuring that the organisation's objectives match the individual needs of team members will keep their motivation high.

Furthermore, it is important to agree on a set of values to lay the foundation of your relationship. Sometimes, these values are taken for granted and leaders miss the opportunity to word them out and check with team members whether they are aligned or not and share the same understanding of their meaning. Some examples of values that

can contribute to creating positive relationships in your organisation:

- Personal development: everyone in the organisation is entitled to continuing development of one's personal and professional competences. This means that challenges and failures are considered as lessons learnt and highlight potential areas for growth. Peer learning is to be encouraged.
- Transparency and inclusiveness: everyone is entitled to express his/her opinion in an honest and open manner. There are no hidden "strategic" processes, limited to an exclusive group of individuals. Sensitive issues are handled with care and in a transparent way.
- Wholeness: every team member is an individual with unique characteristics and a wide range of roles that go beyond the professional role given in the organisation.
- Gratitude: every input to the organisation's development is recognized and acknowledged.
 Gratitude is the source of sustainable motivation for development.

There are various ways to create conditions for above listed values to be effectively embedded in your organisation's daily life. You can use two exercises - Walking talks (Tool 7) and Thank you briefs (Tool 8).

Tool 7: Walking talks

Usually, individual or group talks with team members take place in the office and are structured according to a pre-defined agenda, concentrating on work related matters. Walking Talks¹³ invite you to add a new type of communication to your leader's toolbox, which will allow you to have a more informal interaction with your team members. The objective of a walking talk is to provide an opportunity for more sharing and openness.

¹³ This exercise was inspired by the work of participants in the 2018 EPF capacity-building programme for patient organisations in the field of leadership and governance and more specifically by the special input of Minna Anttonen from Association of Cancer Patients in Finland.

"Walking talks" are a good practice to use with all team members. You can turn it into a regular activity. For example, two walking talks with every team member per year.

What do you need for the exercise?

- A nice place to go to, such as a local park;
- One team member.

How much time do you need for the exercise?

• About 60 minutes.

Instructions:

- Choose a person to invite for a walking talk. Let it be a team member that looks detached and/ or disengaged from the work process;
- Invite him/her to a walking talk. It can take
 place in a nearby park or forest. It is important
 to ensure that there will be actual walking
 involved. Explain to the person that it will take
 nearly one hour, during which you can have
 time to talk on all kind of issues;
- Before the talk, imagine how you would like it to happen. For example, "I would like the other person to feel safe and comfortable to share any point of concern, including points related to my own behaviour as a leader";
- During the talk, try not to impose any agenda.
 Open space for the other person to speak. Try to keep in mind and apply one of the rules of effective communication: 80% of the time is listening, 20% talking;
- After the talk try to observe for some time whether there will be a change in the other person's behaviour. Do you notice more engagement in the work of the organisation?

Tool 8: Thank you briefs

"Thank you briefs" are short statements of gratitude among team members. They are most effective during staff meetings. They help to shift the focus away from self-centred goals and toward reconnecting with the broader needs of the organisation. The essence of the practice is that every team member shares a brief story about someone that he/she have recently thanked or congratulated.

What do you need for the exercise?

- A notebook and a pen;
- A dedicated timeslot in your working week.

How much time do you need for the exercise?

 It depends on how big your team is. Around 1-2 minutes per team member.

Instructions:

At the start of the staff meeting, explain to other team members that you would like to introduce this practice.

- Demonstrate how it is done by telling them about a situation in your daily work, during which you expressed your gratitude to a team member. This demonstration can be further expanded by thanking directly to someone from the participants in the staff meeting.
- Invite others to join in. Remember that every change is slow, so do not push them, but positively encourage them.
- 3. Observe the overall atmosphere following this practice.
- 4. Reflect on how you could further improve it.

This practice is related to the above "Daily gratitude

¹⁴ This practice has been inspired by Frederic Laloux and his book Reinventing Organisations, http://www.reinventingorganizations.com/

exercise", which you could also propose to your team members.

Co-designing and Implementing Decisions

As highlighted above, positive governance is about transforming our decision-making processes by engaging team members from the very beginning. Traditional management and leadership are largely rooted in the understanding that the person on top of the organisation needs to formulate the most important decisions and then delegate their implementation to the team members.

While for some critical situations this approach might still be valid, we would like to encourage you to make space for co-creation and shared ownership on decision-making processes. Good leadership is no longer associated with taking the whole responsibility on your shoulders. On the contrary, by sharing responsibility with other team members, you will have more energy to be creative and expand your horizons.

By opening the decision-making process, you are creating space for collective intelligence to have an impact on the organisation. There are several practices you can use to foster team members' active involvement in this process, namely the following three: Advice process (Tool 9), Coaching circles (Tool 10), Design thinking (Tool 11).

Tool 9: Advice process

According to the original understanding of this practice,¹⁵ anyone can take any decision for the organisation, including spending the organisation's money.

What do you need for the exercise?

 Idea of a potential solution from one team member

How much time do you need for the exercise?

There is not a pre-defined amount of time, but it is good practice to set a reasonable deadline to support the decision-making process.

Instructions:

The only rule to be followed is that the person must seek advice from:

- people who have expertise about the topic, and
- from those who will be affected, and who will have to live with the outcomes of this decision.

Furthermore, the decision-maker must consider all advice seriously, but at the end can take the decision he/she considers the most adequate.

In this advice process, everyone who has something meaningful to contribute is heard. It is very simple: the bigger the decision, the more people need to be asked for advice.

The described practice might need a longer period of time or be embedded as a common process of decision taking in the organisation. You can try to experiment with certain initiatives. For example, announce to team members that they need to decide how to spend a certain amount of money to promote the organisation's activities, by following the rules above.

At the end of this experiment, we encourage you to reflect on what are the concrete outcomes and try to expand the scope of the experiment.

15 The advice process is described in more details by Frederic Laloux in his book Reinventing Organisations, http://www.reinventingorganizations.com/

Tool 10: Coaching circles

Addressing strategic challenges of the organisation can be effectively addressed through embedding coaching circles¹⁶ as an ongoing practice in organisational decisionmaking practice.

What do you need for the exercise?

- A team;
- A physical or online space where to meet;
- A document to keep record of all challenges and solutions identified during the coaching circles.

How much time do you need for the exercise?

Depending on the number of team members to be involved, you can organise several circles running in parallel. Circles usually run for 6 months, meeting once a month for 60 minutes.

Instructions:

Each participant in the circle should choose a challenge that he/she would like to address. During every circle meeting 2 participants present short statements (5 minutes long) on the addressed challenges, focusing on the steps they already took to find a solution, and what are the barriers to overcome. The others are listening attentively to statements and afterwards provide the person with a feedback. Based on this feedback, speakers share whether they have acquired a new perspective on the challenge and future actions. The final stage of the process is a group discussion on possible solutions and next steps.

An indicative step-by-step guide for implementing "Coaching circles":

- Explain to all team members what the purpose of the coaching circle is, i.e. to use the collective intelligence of all, or interested team members, in solving strategic challenges of the organisation. Explain the main phases of a coaching circle.
- Form a pilot circle with team members that you feel are most motivated. Think of a comfortable meeting room to conduct the circles. If you decide to hold an online circle, consider using a platform that will provide good interaction (e.g., Zoom, Skype, GoToMeeting, etc).
- Encourage team members to express their interest in delivering the first two statements on chosen challenges. Have a preliminary talk with the members that volunteered to do it and support them if needed.
- 4. Conduct the coaching circles. You can employ the rotational principle for the moderation of the circle. The first circle might be your responsibility as initiator of this practice, but it is recommended to delegate moderation for future circles to other members.

It is important to ensure that every time two new participants from the circle are sharing their challenges. There will probably be similar challenges, which is completely acceptable.

The coaching circle will also contribute to fostering trust and openness among team members. You are encouraged to ensure representation of staff, volunteers and board members.

¹⁶ The coaching circles has been inspired by Otto Scharmer and a process he calls "case clinic".

Tool 11: Design thinking

This is one of the most powerful processes¹⁷ to foster collective decision-making and implementation in your organisation. Design thinking is a process of co-creating innovative solutions with desired, positive and feasible results. The main "secret" for its success is that it engages team members in a group process, during which each input is valued. The main principles behind this method are optimism, collaboration, empathy and experimentation.

There are various methodologies and activities you can implement using "Design thinking", requiring different amounts of resources and expertise. Here, we would like to provide you a simple 4-step process you can use to foster positive decision-making in your organisation:

What do you need for the exercise?

- Think of a strategic area that you would like your organisation to further progress in. Think of a challenge that is important to solve and that people will be motivated to work on. For example, you might feel there is a need to be more effective in communicating with stakeholders.
- Think of how much time you can spend on this topic or what the deadline for the first outcomes is.
- Announce to all team members that you would like to form an innovation group to find a solution on this issue, and that their involvement will require a certain amount of time.
- Select a suitable meeting place for the design thinking sessions and decide on their frequency.

 You can use the whole process as outlined or elements of it, depending on your concrete needs. There is a wide range of tools available online to help you implement the design thinking concept. For example: https://www.ideo. com/tools.

How much time do you need for the exercise?

- For example, 2 hours per week for a 4-week period. Alternatively, 1-2 intensive days.
- It is up to you to decide how much time should be allocated to the different steps. Usually, a significant amount of time is assigned to getting a clear picture of the concrete challenge, its underlining reasons and the implementation part. Concerning the imagining step (prototyping), it can be organised as reiterative horizontal process. You start implementing your solution and reshape it on an ongoing basis based on the feedback from the environment and target groups.

Instructions:

Step 1 - Feel what the issue is

Select a "big" issue like effective communications, however it is important to be specific and define it as clearly as possible. It is recommended that the issue is concrete and solvable within a realistic timeframe. If you decide to discuss a less specific challenge, people might be demotivated to work on it.

Once this is done, organise the work in one or several smaller groups (5-6 participants) if your team is a large one. It is important to identify an issue/challenge, for which you can identify a clear target group. An example of this could be lack of effective communication with policy-makers at national level. In this case, the target group are policy-makers at national level. Once you have identified the target

¹⁷ There are numerous design thinking schools on global scale, which inspired current description. The most famous schools referred to are: IDEO and Design for Change.

group, you can continue talking and exploring the specific characteristics of the target group, so that you can connect with some of the root causes of the issue at hand.

At this point, it is important to encourage the innovation group to plan data collection activities on the target group. These activities can take the form of online surveys, individual interview, focus groups, etc. Try to focus on gathering first-hand information that expresses the needs of the target group.

Step 1 Outcome:

The outcome of this step would be to define a clear challenge that your team is capable of addressing, and indications of what are the root causes of the challenge, which will help you to formulate good solutions.

Step 2 – Imagine original and sustainable solutions

At this step, you discuss among your team members what the ideal scenario for you as an organisation would be if the challenge you are tackling would be solved. This process opens the team's creativity and allows team members to think more freely.

Now, invite every member to think of as many solutions to the identified challenge as possible. Invite them to think about solutions that are brave and non-traditional. Following the individual creative process, open a consultation process during which participants can select a certain number of more promising or inspiring solutions. The process facilitator could ask people to vote on the ideas, rank them, or write their name next to the solutions that they consider more promising. Once the most promising solutions are identified, they will be more carefully evaluated in small teams. Each team will need to check whether a given solution is feasible

considering the available resources and expertise within the team.

Afterwards, you invite the team members to create a prototype for the solutions that passed the feasibility test. The prototype can be described in writing or visualized through artistic means. When prototypes are ready, the teams present them to each other and collect feedback on their fine-tuning.

Finally, each team is encouraged to introduce the prototype idea to the target group identified and collect their feedback as well.

Step 2 Outcome:

The outcome of this step would be to have a prototype idea acceptable to the target group.

Step 3 – Do what is necessary to implement the solution

At this step, prepare an action plan to implement your prototype in practice. For example, if your solution is creating a database to gather all the key contacts, now is the moment to think of the concrete activities to be carried out. Following the development of the plan, you can proceed as one team or divide yourself in small teams to work on the real implementation.

This stage can also be considered as piloting, since you are implementing the solution for the first time. It is recommended that you place strong focus on collecting feedback for your solution from various sources.

Step 3 Outcome:

The outcome of this step would be to have an action plan and a pilot edition of your solution.

Step 4 - Evaluate and mainstream

As soon as your solution is piloted (e.g., database created), you can meet with the whole team to evaluate your experience and the results achieved. This will provide you insights on what can be improved and how to make this solution sustainable.

Step 4 Outcome:

The outcome of this step would be to have ideas for sustainability for the piloted solution. If you feel uncertain about any aspect of design thinking, you can contact design thinking communities in your country¹⁸.

Reigniting the Board

Often, the main involvement of an organisation's governing Board members is limited to attending Board meetings and being available for online/phone consultations on issues related to strategic management and reporting. While this is an important contribution, it might sometimes lead to gradual disengagement with the organisation's mission and activities. Board members are usually people with high-level expertise in many areas, which can be of great help to any organisational leader. Reigniting their enthusiasm and dedication will allow for this expertise to be used in a more comprehensive manner.



There is no one-way solution on how to achieve this desired outcome. Some patient organisation leaders feel that the process of motivating Board members starts with their successful selection and induction. Others believe that this can be achieved by inviting them to represent the organisation at events with patient representatives and the wider public. There are also supporters of the idea that engaging Board members in international trainings and conferences serves as a motivation trigger.

Looking at current practices of patient organisations, you can use the following questions to guide you in the process of shaping positive relationships with your Board:

- Do you feel that some of the Board members need more close communication to stay on track? If so, try to organise individual communication sessions with each member.
- Do you feel that the agenda of your Board meeting is too formal? If so, think of introducing non-formal topics that would allow for better knowing each other, open space for trustful dialogue and feedback.
- Do you feel that most of the communication is via e-mail correspondence and audio calls?

 If yes, think of ways to introduce more face-to-face communication formats. For international umbrella organisations this might be a challenge to organise, but still there are wide range of online communication platforms that allow at least to see each other and communicate in a more dynamic way (e.g., Zoom, Skype, GoToMeeting, etc.).
- Do you feel that in most cases you are leading the whole communication process? For example, moderating Board meetings, preparing the agenda for Board meetings, sending circulars letters, etc. If so, you can try to distribute some elements to the Board members, which will nurture

⁸ One of the global networks in design thinking for social impact is OpenIDEO. Through this network, you can identify design thinkers in your region that are dedicated to social innovations. For more information: https://www.openideo.com/

their sense of ownership of the process and motivation to be more active. For example, you can introduce a rotational moderation model of Board meetings, which will ensure that every meeting will be moderated by a different Board member.

• The most important aspect of building fruitful relations with a Board member is the induction phase. Induction sets the ground for sustainable engagement. It serves two purposes: sets clarity on roles and responsibilities and establishes a first level of trust with the organisational leader and the Board members. You can use the Board members induction guidelines (Tool 12) to frame the process.

Tool 12: Board members induction guidelines

An effective induction process would bear several key characteristics:

- A formal introduction of newly appointed Board members to their position by the Chair.
- A clear statement of the expectations for and the responsibilities of new members.
- A deliberate, systematic and rapid familiarisation of new members with the organisation and operations of the Board (including a briefing by the chair, the provision of appropriate supporting documentation and the assignment of another Board member to act as quide or mentor).

New Board members can be reluctant to contribute until they feel they know more and are better acquainted with their colleagues. If a new Board member is left to "sink or swim" and therefore is not able to fully contribute to the Board's deliberations, the board is under-performing. It also means that the energy and ideas of a new Board member do not have the beneficial impact they should. The Board will lose a and valuable opportunity to benefit from new members' fresh perspectives.

Here below you can find an indicative checklist of items to be presented to the new Board member:

- organisation's values and history;
- organisation's governing documents, policies and procedures;
- organisation's financial reports and strategic plan:
- organisation's facilities (with provision for visits to those facilities if possible);
- structure of the Board (positions held, and roles and responsibilities of those positions);
- list of all Board members and their contact details (biographies, if available);
- calendar, or schedule of forthcoming Board meetings (date, time and location including whether online meetings) and other significant events;
- details on how the Board operates in practice (for example, how documents are circulated, amended, and stored);
- previous minutes of Board meetings (the last six to twelve months are likely to be the most useful);
- any specific Board policies and procedures (such as attendance policy, disputes, delegations, and confidentiality).

Every Board member comes with a specific set of knowledge and skills of value to the organisation. Still, in most cases new Board members might lack certain competences to be fully involved in organisation's development. As organisational leaders you can arrange for regular discussions about the skills and knowledge that each member brings and discuss if there are any gaps, and if training would be necessary.

You may also consider introducing an annual review of all Board members' performances, such as performance assessments you might undertake with the staff (if applicable). This is another good way to identify gaps in skill or knowledge. The

following areas may be considered in these discussions and reviews:

- Knowledge of the field;
- Community affiliation/Access;
- Financial literacy;
- Fundraising;
- Government relations;
- Human resources:
- Leadership;
- Legal;
- Lobbying;
- Communication;
- Organisation management;
- Risk management;
- Strategic planning;
- Technology/IT.

Keeping up with Members

Members are a key focus point in any organisation's mission. Still, there are many examples in practice, which show how connections with members gradually become loose and in the best scenario are merely a formality. Whether we are referring to individual or organisational members, there is an ongoing risk for the integrity of our relationships. One way to mitigate this risk is to employ an active engagement approach, which is characterised by more regular involvement of members in an ongoing consultation process.

As leaders, you can provide members with the opportunity to comment on your statements, to express their support or disagreement, and to provide any additional views they may have.¹⁹

General consultation methods include: face-toface meetings; general assemblies; workshops; working groups; teleconferences; surveys; polls; written consultations; and collaborative platforms or online shared documents (Yammer, Slack, Google docs. Zoom, etc.).

For a consultative process to be legitimate, it needs to give an appropriate and specific amount of time to respond to the consultation.

Create a co-creation atmosphere by defining the consultation process together with your members:

- What are the instances/topics on which your members want to be consulted?
- What is an acceptable timeline for them to review the materials/statement you send them?
- Through which channels do your members prefer to be consulted?

The consultation process does not stop when you receive answers from your members. You will need to integrate the comments received, share them with other members, and provide feedback on the comments received, and why the organisation decided or not to take them into consideration.

For members to feel the ownership of your network, they need to know that they are shaping its policy work, contributing to its strategy, and that their opinion is taken into account. By dedicating time to build a positive feedback loop, you reduce the distance between them and the organisation and foster their sense of belonging of organisation's work and achievements.

Reconnecting with Volunteers

More often leaders of patient organisations face difficulties in recruiting volunteers. The main challenge is that their dedication to the organisation's activities often decreases over time.

Volunteers work best when a project or an activity incorporates their ideas or when they initiate it. They need space and sense of both

 $19\ This section of the toolkit is inspired and based upon EPF Transparency Guidelines, 2017, http://www.eu-patient.eu/library/toolkits/$

freedom and inclusiveness. This requires constant communication effort from you as leaders.

Metaphorically, volunteer engagement is a marathon, not a sprint. It demands investing and long-term planning. In a sense, it brings resources in terms of human support for certain activities, but also needs resources itself to be sustainable and effective

The levels of involvement of volunteers are diverse. They can be engaged more regularly, or work on specific tasks only. One thing remains constant: **we must be able to rely on them**.

Organisations working with volunteers share the same pattern of volunteers coming for a period of time and then leaving the organisation. This flow has to be accepted as a natural state and be managed.

There are various approaches in that regard. We encourage you to integrate a proven practice, by pairing a newcomer with an experienced volunteer. The newcomer will learn through job shadowing how to implement his/her tasks, saving you time to give instructions. The experienced volunteer will transfer all the know-how acquired, so if he/she needs to leave the organisation, the know-how stays in the organisation and the newcomer will feel immediately welcome and part of the community.

Additional practical tips²⁰ you can consider, to ensure engagement of volunteers:

- Show that volunteering with your organization offers both tangible and intangible rewards;
- Pick specific volunteers for specific jobs that you know they will like and be good at;
- Offer volunteers their choice of jobs, or, let the volunteers create their own job descriptions;
- Offer both initial and ongoing training and supervision;
- Provide opportunities for volunteers to assume leadership roles in particular projects or situations and encourage and help them to expand their skills;
- Ask current volunteers to describe the benefits and satisfaction they get from volunteering and compile their responses to give to potential volunteers;
- Include volunteers in any social activities (lunches, lunchtime card games, after-work gatherings, etc.) that occur when they are volunteering;
- Hold Volunteer Appreciation celebrations and give volunteers small gifts for completion of each contracted period of service (often a year, but it's up to the individual organization).



20 The tips are formulated by the Community Tool Box, a service of the Center for Community Health and Development at the University of Kansas, https://ctb.ku.edu/en

4. DEVELOPING YOUR **EXTERNAL COMMUNICATION**

In this chapter, we invite you to embrace an ecosystemic leadership approach towards your external environment. Healthcare is a complex systemic issue and we need to work together with all players involved to make a real impact. Patients and patient organisations are arguably the most untapped resource that we must unlock the path in designing more efficient healthcare systems.21

Eco-system awareness stems from understanding that the traditional model of having counteracting interest groups should be replaced with a model calling for more unity in the name of the common wellbeing. Metaphorically, the circle of trust should be widened to cover all stakeholders working in the field.

Your contribution as an organisational leader will be to act as an agent of change, demonstrating in practice that sustainable and positive results are only feasible through collaborative conversations, empathy and co-creation of decisions and solutions.

There are several focus areas to consider in this task:

- 1. Seeing Points of Impact;
- 2. Recognising Organisational Value;
- 3. Co-creating Solutions.

Seeing Points of Impact

Operating in a complex and dynamic system such as the healthcare system requires having a clear understanding of the environment in which you are operating in. This analysis will provide you with hints on which areas of actions you could focus to get maximum results. In systems thinking, these areas are called leverage points in the system, where a small shift in one point can produce big changes in everything.22

To identify the point/s, where you can exert strongest impact you will need to spend time on systems analysis. One simple tool to use is Behaviour over time graph (Tool 13). It can be combined with an environmental analysis tool, called PEST analysis.23

Tool 13: Behaviour over time graph

This tool²⁴ can be used in combination with the Iceberg tool for mapping underlining patterns and root causes. It allows you to reflect on the factors triggering or keeping certain events and developments and see where you and your organisation can exert maximum impact.

What do you need for the exercise?

Two sheets of paper and something to write with.

How much time do you need for the exercise?

The exercise can take 1-2 hours if you have collected relevant information to map the historical development of the issue at hand.

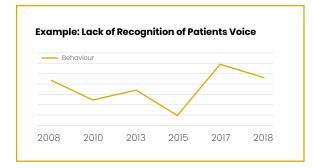
Instructions:

The process follows several main steps, which can be adopted to your personal style and understanding:

Choose a long-standing issue that you would like to work on. For example, the lack

²¹ EPF Impact Report 2018, http://www.eu-patient.eu/library/impact-report/22 This section is inspired by the systems thinking school around the world with distinguished representatives like Peter Senge, Otto Scharmer, Donella Meadows, etc. Source for the definition of a leverage point: http://donellameadows.org/archives/leverage-points-places-to-intervene-in-a-system/
23 More information about PEST analysis can be found in EPF's toolkit on Building National Coalitions of Patient Organisations, http://www.eu-patient.eu/
globalassets/library/publications/epf-toolkit_nationalcoalitions.pdf
24 The tool has been inspired by systems thinkers like Peter Senge, https://executive.mit.edu/faculty/profile/30-peter-senge

- of recognition of the patient's voice by policymakers.
- Chose a period that you would like to reflect on and see how this issue has developed. For the current explanation, let us take a 10-year period (2008-2018).
- Draw a simple line graph. "Time" must run along the horizontal axis. The "behaviour," the variable that changes over that time, is plotted on the vertical axis. The purpose of the graph is to picture how the behaviour/the state of the issue we observe changes as time progresses. Here is a sample line graph:



- Looking at the reviewed period mark the moments, when the voice of patients was almost of no influence on the policymakers' agenda and times when it was present. This is a subjective assessment, based on your expertise. In the above sample, 2015 seems to be the year of lowest influence and 2017 with highest.
- Try to explore, why the patient's voice was less heard in 2015. What are the key factors for that state? For example, a change in governmental policy, bad financial situation of patient organisations, low public interest in health system reform, low motivation of patients to participate and to provide enduser perspective. The list is only limited to demonstrate how the instrument works.
- On a separate sheet of paper, write down the main factors and check, which ones your organisation can address. From the above example, we can say at first glance that there

- are two factors that seem to be within your scope, i.e. low public interest in health system reform and low motivation of patients to participate.
- Take time to evaluate, based on your existing resources (time, finance and human resources), which of the two factors can turn into your acupuncture/leverage point, allowing you to make a strong impact with limited resources. Choose the point that you will start working on.

Additional methodological guidelines:

- The current instrument enables you to quickly look at the environment and see where your potential intervention areas are;
- You can use it on your own or together with your team members.

Recognising Organisational Value

There is an ongoing risk for leaders of patient organisations to fall into the trap of regular non-governmental organisations to feel dependent on other stakeholders, because of the lack of resources or influence.

Many patient organisations attend meetings with stakeholders feeling like the "weaker" interlocutor in the discussion. This is the wrong approach. You are not asking for a favour, but you are bringing something to the table. You are offering expertise and a perspective that the other side currently does not have. Trust your worth and go into discussions as an equal!

It should be strongly highlighted and always reminded that patient organisations are invaluable partners in the shaping of national and European health systems, providing input through stakeholder advisory groups, expert panels, European and/or national government public consultations or institutional meetings.

Patient organisations are able to help policy-makers understand the experience of living with a disease or a condition. They use this "end-user perspective" to promote the interests of patients at all stages of policy development and in a range of institutional settings, therefore representatives of patient organisations should know and trust their worth when walking into a meeting.²⁵

Co-creating Solutions

When we interact with stakeholders, we are focused on making our demands and messages clear and heard. Moreover, in this interaction we are with high hopes that our requests will be positively addressed, and this will support the implementation of our organisation's mission. This is a valid motivation, and there are many examples that it still can lead to good results.

Still, for these results to be sustained and further multiplied, another approach can be adopted. It is largely related to transcending the practices from your internal work to developing a new leadership style and embedding positive governance in your organisation to your relations and activities with stakeholders.

In this new perspective, stakeholder management is not seen as a pre-determined strategy or scenario you devise and implement but is a result of your collaboration with stakeholders from the very beginning.

Several key principles should be taken into consideration:

- All needs of all participants in the collaboration process are communicated clearly and equally, and there is a mutual acknowledgement of needs;
- Everyone participates in the creation of solutions and is motivated to contribute to their implementation;
- Solutions serve all interests and are aiming to the common good.

Adopting an empathic approach towards your stakeholders will help them connect their individual goals and needs to your cause and your organisation's projects.²⁶ Try investing time in cultivating relationships starting with stakeholders that you feel already value, and that support your organisation. These stakeholders will make the most valuable contribution to your organisation in the end.

You can use many of the tools already highlighted in the current toolkit to enable you to engage your stakeholders in a co-creation process such as: Empathy Map, Walking Talks, Thank-You Briefs, Coaching Circles and Design Thinking.



²⁵ The Added Value of Patient Organisations, EPF Report, 2017, http://www.eu-patient.eu/library/
26 The idea on empathic approach towards stakeholders emerged from the EPF Fundraising Toolkit For Patient Organisations, 2016, http://www.eu-patient.eu/library/toolkits/

TEN RULES OF QUALITY LEADERSHIP

In this chapter, we present to you ten rules for quality leadership, which can support you in your daily leadership journey. The rules synthesise practical experience and lessons learnt by leaders of patient organisations that took part in the 2018 EPF Capacity Building Module on Empowering Leadership and Positive Organisational Governance.

- 1. Change takes time. Good leaders need to be patient.
- 2. Adopting new mindset and behaviour contribute to the whole organisation's development and transformation.
- 3. Self-reflection helps in raising awareness of one's needs and those of other people. It helps you overcome negative and imaginary barriers.
- 4. Communicate your needs to staff and Board members.
- 5. Do not be afraid of admitting your weaknesses to other staff members.
- 6. Trust your instincts and intuition. You will find more answers to challenges, if you listen to yourself more.
- 7. Make more time for yourself and don't work as much. Take it slowly.
- 8. Be positive and open to multiple perspectives.
- 9. In some cases, it is better to stop putting efforts and explore the reality from a different angle.
- 10. Let go of controlling everything and do not overthink. Try to find the balance.



REFERENCES

EPF Publications

The Added Value of Patient Organisations, EPF Report, 2017,

http://www.eu-patient.eu/library/

Driving Better Health for Patients in Europe, EPF 2017 Annual Report,

http://www.eu-patient.eu/library/Annual-Reports111/

EPF Transparency Guidelines 2017,

http://www.eu-patient.eu/library/toolkits/

EPF Impact Report 2018,

http://www.eu-patient.eu/library/impact-report/

EPF's toolkit on Building National Coalitions of Patient Organisations,

http://www.eu-patient.eu/globalassets/library/publications/epf-toolkit_nationalcoalitions.pdf

Books

Scharmer, Otto. The Essentials of Theory U: Core Principles and Applications. San Francisco, CA;

Berrett-Koehler Publishers, 2018

Laloux, Frederic. Reinventing Organisations, 2014

The Field Guide to Human-Centered Design, IDEO.org, 2015

Meadows, Donella. Thinking in Systems, 2008

Articles

Scharmer, Otto. Leading from the Emerging Future, 2013,

http://www.ottoscharmer.com/sites/default/files/Ego2Eco_Intro.pdf

What VUCA really means to you?, Harvard Business Review, 2014,

https://hbr.org/2014/01/what-vuca-really-means-for-you

Videos

Theory U - Learning from the future as it emerges, Otto Scharmer, TEDxTUHH,

https://www.youtube.com/watch?v=GMJefS7s3lc

Peter Senge: "Systems Thinking for a Better World" - Aalto Systems Forum 2014,

https://www.youtube.com/watch?v=0QtQqZ6Q5-o

Tim Brown: "Designers Think Big", 2009,

https://www.ted.com/talks/tim_brown_urges_designers_to_think_big

Linda Hill: "How to Manage for Collective Creativity",

https://www.ted.com/talks/linda_hill_how_to_manage_for_collective_creativity

NOTES



The European Patients' Forum
(EPF) is the united patient voice
in Europe. Since 2003, we work
with patients' groups in public
health and health advocacy
across Europe. Our 70+ members
are national coalitions of patients
or represent specific chronic
disease groups at EU level.

European Patients Forum Chaussée d'Etterbeek 180 B-1040 – Brussels BELGIUM

Phone: + 32 2 280 23 34

Twitter: @eupatientsforum Facebook: /EuropeanPatientsForum

www.eu-patient.eu

info@eu-patient.eu

Q www.eu-patient.eu

f www.fb.com/EuropeanPatientsForum

https://twitter.com/eupatientsforun

www.youtube.com/eupatient