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About this guide

This guidance document is designed to provide practical advice for patient group organisations and advocates to support them in creating positive change for the communities they represent.

The recommendations included in this guide are based on the experiences and work of Maja Kocić, President of Lymphoma Patients Association (LIPA), in Serbia.

For more information about Maja's advocacy work on behalf of people living with cancer in Serbia, please click [here](#) to watch the full video mini-series.

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Defining your motivations and goals

1. Why do you think it is so important for organisations, at the start of their advocacy journey, to define their goals?

- It can feel overwhelming starting out and knowing where to begin, so defining your goals is really important to help you decide where to focus your efforts.
- Having a few, achievable goals is important. Aligning these goals and objectives with your key stakeholders will help in making these a reality and create mutual benefit.
- It helps to think of your goals as the long-term results that you are trying to achieve, on behalf of people living with cancer or other diseases, and those who are close to them.

2. What tips would you give to patient organisations who face setbacks throughout their advocacy journey?

- Before defining your objectives, you need to establish not only what is important for you, but also what is relevant to other stakeholders, whose agenda might touch upon your issue.
- No matter how small your organisation is, you are capable of being/becoming a catalyst of change.
- Don't give up!



Alliances/Multi-stakeholder approach

3. Why do you think it is so important for people from the community to join/support their local patient organisations?

- Patient organisations such as LIPA are voluntary and benefit from the support of the community. This will help build a strong voice and be heard, as well as support you with becoming an equal partner with a seat at the table where decisions are made.
- Patients can learn so much from each other when we work together.

4. How would you recommend a patient organisation identify and prioritise the different stakeholders that they should be engaging with?

- Patient organisations need to decide on a case-by-case basis when better to address the broader picture in alliances across diseases. It is worth

remembering that health policy decisions are often not made to address disease-specific needs.

- All healthcare and ecosystem stakeholders must work together - patients, healthcare professionals, policymakers, decision-makers and societies, industry and academics.
- The media can play a crucial role in getting your message across to your audience.
- It is important to collaborate with patient groups who have the same interests/challenges as you.
- Always be polite, professional and transparent - this is so important to build relationships.



Use of resources

5. Based on your experience, what tips would you give to patient organisations with limited resources to achieve/advocate for change?

- Organisations do not need extensive concrete resources such as funding, human resources etc, as long as you are passionate about your cause.
- Look at a collaborative approach with other organisations and individual experts with similar goals.
- By developing positive relationships with other stakeholders, patient organisations can sometimes tap into their resources too, for relevant information and advice.
- Don't be afraid to take action - no matter how big or small your organisation is; passion will inspire and trigger engagement.



Importance of data/data sharing

6. What tips do you have for organisations who want to create patient-led evidence? (e.g. how can organisations know what data is important to collect and how can they use it?)

- Patient data is so important because you can use it to emphasise your position, and make comparisons between other organisations, regions and/or countries.
- Find out what your relevant key stakeholder group and related individuals need as evidence, in order to understand and ideally join your cause and also support you and your organisation's goals.

- Define the evidence needed: check what is already available in your network, in your own country and/or neighbouring or other countries which could support your cause and potentially think about what evidence you could generate as an organisation, coalition or with other partners with a view to build a consistent long-term evidence base.



Working with policy makers/the Ministry of Health

7. What should patient organisations consider to effectively engage with healthcare regulators?

- Prioritise who, within the healthcare ministry, is a 'must' to engage with, and who are 'nice to have on board'. This helps patient organisations target their time and resources.
- Engaging with healthcare regulators is not a one-off activity, it's a long-term process which needs to be prepared and researched in order to achieve desired results.
- Maintaining the dialogue with key policy makers following engagement is crucial to positioning your organisation as a trusted and reliable partner.
- Sustain the dialogue even when there is no issue at stake.

8. Based on your experience in Serbia, what are your top 3 tips for approaching and working with health ministers?

- We were told - 'Do not bring problems, bring solutions'
- Work with other organisations who have the same experiences, challenges and goals, even if these organisations represent different disease areas.
- Building on the need for evidence in general and patient-led evidence in particular; it is so important to take reliable and fit-for-purpose evidence to emphasise your position/need.



Working with national and international patient organisations

9. How should patient organisations approach working with other national and international organisations? Why are these partnerships important?

- Local organisations should connect with other groups in the region, even if it is for a different disease area, as this makes the collective patient voice more powerful and ensures learning, experience exchange and scaling of ideas and solutions.

- Smaller organisations, especially in poorer countries, benefit because we can access and share resources we may not otherwise have.
- Look out for international and/or global networks to join that can help support your cause. These networks are invaluable for boosting your learning as an individual, organisation and community.
- Connecting with international organisations can also provide a platform to share your experiences and foster collective learning and dialogue with a view to a “Think global, act local” approach.
- Connecting LIPA with the Lymphoma Coalition (as global organisation) provided mutual benefits as these organisations can also learn from grassroots organisations too.

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About IEEPO and the CHANGE domain

The CHANGE domain and Changemaker video series is an initiative launched by the International Experience Exchange with Patient Organisations (IEEPO). IEEPO is a platform of engagement for the international patient community.

IEEPO aims to support the global patient community by providing learning opportunities around global trends in healthcare systems, creating a forum for experience exchange and co-creation, fostering connections with stakeholders from across and outside the healthcare ecosystem, and empowering patient communities to be strong and impactful partners in transforming the future of healthcare ecosystems.

The IEEPO CHANGE domain enables patient communities to hear how different experts and advocates have affected health policy and created healthcare transformation and positive change for their communities. This is reinforced by the concept that global health policy is shaped by what is happening on the ground through evidence based patient advocacy; a ‘Think globally, act locally’ approach.

As part of the CHANGE domain, the Changemaker video series will showcase the work of patient organisation leaders, to inspire and provide practical advice for patient group leaders advocating for change for their own patient communities around the world. The videos will be hosted on www.IEEPO.com