

Patient advocacy webinar



**Tamsin
Rose,
Tamarack
November
2018**

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What we will cover today

- **How change happens**
- **What is the issue**
- **What do you want to achieve**
- **How patient advocacy differs**
- **The importance of stories**
- **Key elements of an advocacy strategy**
- **How to work well with your Brussels team**

Why are we here?

- ❖ The status quo is not acceptable (or we would not be here today)
- ❖ Change does not happen automatically (or it would have happened already)
- ❖ We can imagine something different, something better
- ❖ The future has not happened yet so we can change it

Why is change so hard to achieve?

- ❖ The status quo 'works' because it is known. Change is unknown, you have to prove that what you want will 'work better'
- ❖ Even small changes can have unintended consequences and might be dangerous
- ❖ Some people or organisations benefit from the status quo and will oppose change
- ❖ Change = loss of control = unpredictable = fear
- ❖ Change requires effort, negotiation, compromise, leadership
- ❖ No wonder helping people and organisations to change is a specialised profession

Explore the issue in context

- Who is affected by it ?
- Are patient experiences similar or different?
- Can we collect information about it?
- Is there good practice to be copied?
- Is there evidence of the impact/cost/harm?
- What needs to change – law, policy, clinical practice, reimbursement rules, admin barriers?

The key elements for advocacy

The problem (What is happening/when/why)

What do you want to achieve

The audience (stakeholders)

The information/evidence/data

Your key messages (what you want)

Personal stories (how it affects you, why it matters)

Actions

Communication tools

What is patient advocacy?

“Nothing about us without us”

Advocacy in all its forms seeks to ensure that people, particularly those who are most vulnerable in society, are able to:

- ★ Have their voice heard on issues that are important to them.
- ★ Defend and safeguard their rights.
- ★ Have their views and wishes genuinely considered when decisions are being made about their lives.

Advocacy at what level?

Individual advocacy focuses on changing the situation for an individual and protecting their rights

Systems advocacy means efforts to change policy and practice at the local, national or international level; to change the situation for groups of individuals who share similar problems

Both systems and individual advocacy are critical for change to happen.

Successful advocates communicate

- Why change is needed and why now.
- What you want to happen and how things will be different.
- Who will benefit and who will lose out.
- What it will cost and who will pay for it.
- What you want someone to do and when they should do it.
- How you will help them.

The framework for action

- ❖ Understand the potential winners and losers of a change.
- ❖ Identify appropriate windows of opportunity for advocacy.
- ❖ Build coalitions and alliances to multiply the impact of messages.
- ❖ Develop arguments appropriate to target audiences.

Do your homework – invest time in intelligence gathering

- ❖ **Policy-makers** – where are they in their career? What are their ambitions? Have they made any issues their own? Are they looking for a legacy? Is their personal capital to be gained?
- ❖ **Media** – get to know which journalists cover what type of story, think about appropriate angles to your story and then pitch it.
- ❖ **Timing and context** – are there elections coming up? Could this be a 'good news story' for an embattled government or media hungry opposition?

The power of patient stories

- Share the real experience of living with a disease
- Highlight the impact on individuals, carers and families
- Tackle taboos and stigma
- Encourage empathy and understanding
- Puts a face and a history to statistics

Why are stories effective?

They are **vivid** and **real**, they correspond to the way that people think. They can illustrate facts and statistics.

A story **outlines an issue** and **potential solutions** in a simple way that people can understand.

Stories involve a **catalyst** that helps make transformation possible, identifying the **actions** that the audience can take to ensure the positive outcome.

Select the stories to match the background, experience, occupation, and age of the audience as well as the nature of the occasion.

Irish Referendum on abortion



“More than three-quarters said they were influenced by personal stories they heard in the media or by people they knew.” The Guardian

“Together for Yes” strategy

“We were very clear that we would build our messaging on the basis of the focus group research. The three key messages were care and compassion and change, the 3 Cs. Narratives have been developed and built around each one.”

“We were very clear that what would help people was hearing the reality of couples and women who went through very distressing experiences.”

“We knew how important those stories were from the marriage equality referendum and also from polling of social sexual issues elsewhere.” Ailbhe Smyth, Director

What are the elements of storytelling?

Stories need to be **compelling**, they show **opportunities for change**. You need to find a theme that resonates with your audience.

Important elements include the settings, characters, sensory information, the situation and place.

Think about the biography or back history of the situation. Note any conflict, drama, opposing forces, choices and actions, solutions.

Highlight the interaction between characters, keep it concrete.

Why is the story interesting and powerful? As human beings we are interested in other people, stories help us to identify with those affected and generates shared emotional responses.

Hard challenges to overcome

Ideology: despite accepting the need for action and the type of action required, policy-makers may refuse to act because they do not believe in government regulation, think that action is better taken by other actors (self-regulation) or at different levels (global, national or local).

Timing : policy-makers can lack courage at critical moments because of electoral timetables.

Conflict of priorities : Not 'their' issue, unwilling to spend their social or political capital, more urgent issues to resolve.

Change means learning to do things differently

What can we learn from models of behaviour change ?

- Repetition is needed (minimum 6 months)
- Intention with focus and energy delivers results
- Persistence, it may take several attempts
- Attention to the ecology, a change can unbalance other issues or relationships

Summary: The key elements

Using your evidence to create the key elements of an advocacy strategy including:

- Goals,
- Roadmap/timing,
- Partners,
- Intelligence,
- Champions,
- Opponents,
- Timing,
- Messaging.



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From me to EU



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How to use your Brussels team

- Your guides to the Brussels bubble (who does what, when and how)
- Insight into how the EU works (understand EU jargon, the EU/national/local powers)
- Coordinate activities across countries (shared advocacy goals)
- Early intelligence about what is coming up on EU agenda (Presidencies, Commission)
- Help to access your MEPs & Perm Rep

How to support your Brussels team

- Participate in joint actions (petitions, signed letters)
- Disseminate information in local languages
- Collect patient stories and testimonies
- Reply to consultations on policy or legislation
- Complete online surveys and questionnaires
- Share examples of what is working and what isn't at national level