Barking up the right tree on access, policy & research: Why evidence-based advocacy?

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That's what many people still think patient advocacy is all about.
What patient organisations really do…

Support & inform patients

Advocate for better health policy and access

Help research to do the deliver what patients need
Stories and emotions may open doors – but will they change the outcome?
„Patient knows best!“ – the trap of subjectivity in patient advocacy
Why does collecting patient evidence matter?

- **Patients’ preferences** are very different to other stakeholders - individual and heterogeneous

- **Patient value will differ between diseases and within one disease**, according to stage of disease, and stage of life

- Considerations around treatment modalities, tolerance towards side effects vs. treatment effects, and psychosocial well-being vary largely (and may not be obvious to other stakeholders)

- **Industry, clinicians and authorities** increasingly need to understand and justify the value of a medicine (particularly in diseases like CML)

- **We need to be able to measure preferences** and take them into account into decision-making to help access and improve outcomes
Why does collecting patient evidence matter?

What is currently measured & regarded:
- Safety
- Efficacy
- (Cost) effectiveness
- Survival benefit (PFS and OS)
- Risks
- Health-related quality of life

What is often unknown:
- Do patients want to take the treatment?
- Is it acceptable to patients?
- Is the administration acceptable?
- Does it capture emotional and psychosocial impact?
- CML-specific issues
- Patient value
Evidence-based advocacy

Targeted advocacy

Really good data

The right packaging
What do you mean by „targeted advocacy“?
Know your trees – and bark up the right one

Somebody should do something about this!

- „The government!“
  Regional level vs. national level
- „The clinicians!“
  Medical societies vs. study groups vs. individual clinicians
- „The industry!“
  Global vs. regional vs. affiliate vs. industry associations
- „The CML community!“
  (CML-specific action vs. cross-disease alliances)
„Really good data?“ – what type of evidence helps your target group to make better decisions

- Data that is **spot-on** to influence specific upcoming decisions of the decision-makers
- Data that **represents your community**, or a defined subgroup
  - How do individual patients value benefits and risks?
  - Are there groups of patients with similar values in the population?
- Data that **can’t be disregarded** just for methodological reasons

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*Postmus et al. CPT, 2015*
What do you mean by „the right packaging“?

Banging your head against the wall may not be the best way getting your message across.
<table>
<thead>
<tr>
<th></th>
<th>Negotiation tactics and building your case</th>
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<tbody>
<tr>
<td>1</td>
<td>Define the outcome and a possible retreat outcome</td>
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<tr>
<td>2</td>
<td>Consider the second position, possible resistance</td>
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<td>3</td>
<td>Be clear with your reasoning, the benefits, the risks</td>
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<td>4</td>
<td>Present evidence and proof to reassure</td>
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<tr>
<td>5</td>
<td>Make your delivery compelling</td>
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<td>6</td>
<td>Explore barriers and resistance with empathy</td>
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<tr>
<td>7</td>
<td>Represent your case, ask for commitment</td>
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Source: Alison Dawkins, 360 Flexible Training Solutions @ ESO Masterclass (2018)
Evidence-based advocacy

Advocating in a targeted, evidence-based, well-educated and professional manner, and measure impact and outcomes of what we do.
Data, not just opinions!

Evidence-based advocacy at CML Horizons:
Session 1: How to GENERATE the evidence as a patient group
Session 2: How to USE the evidence in advocacy