



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?

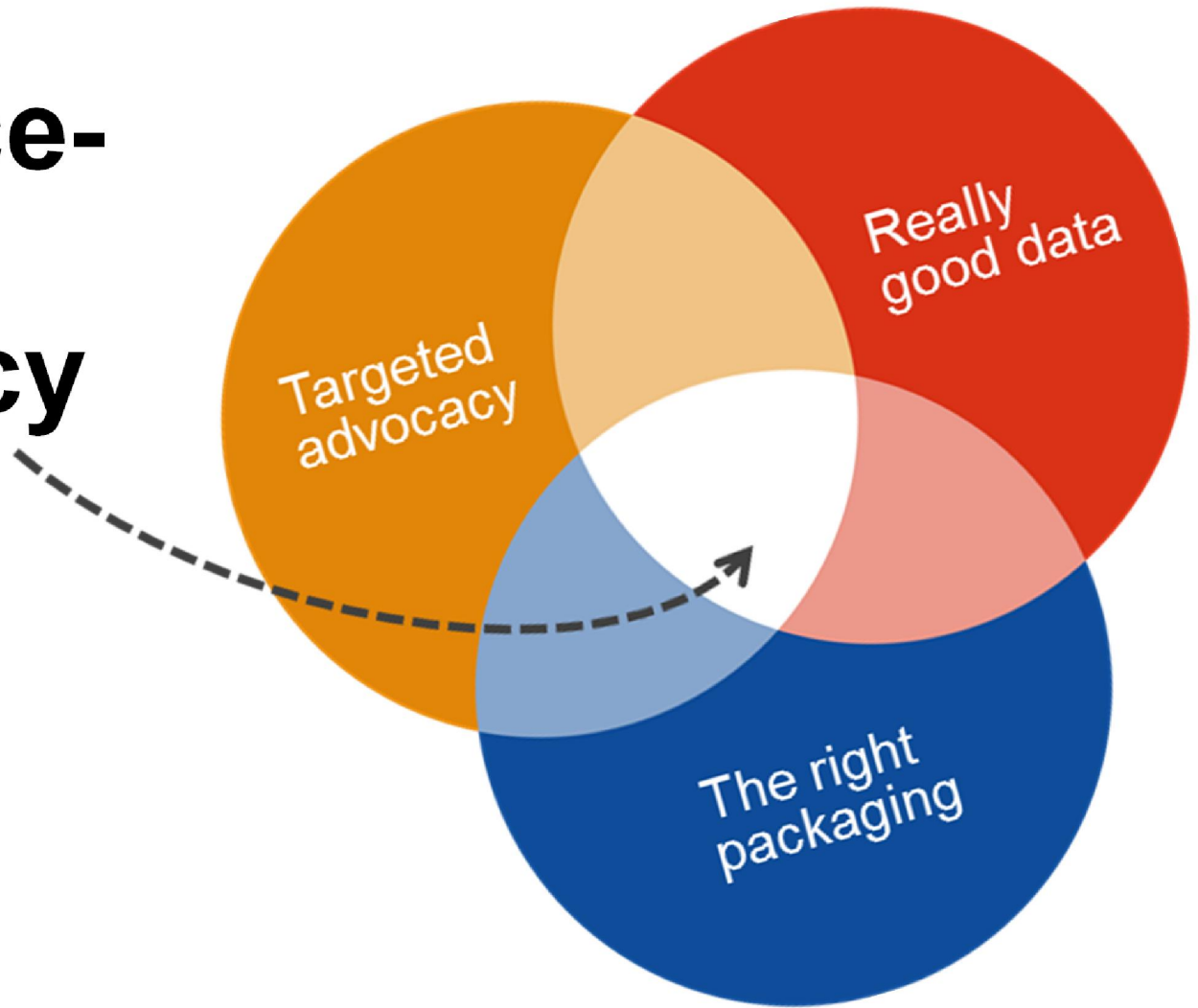
What is currently measured & regarded:

- Safety
- Efficacy
- (Cost) effectiveness
- Survival benefit (PFS and OS)
- Risks
- Health-related quality of life

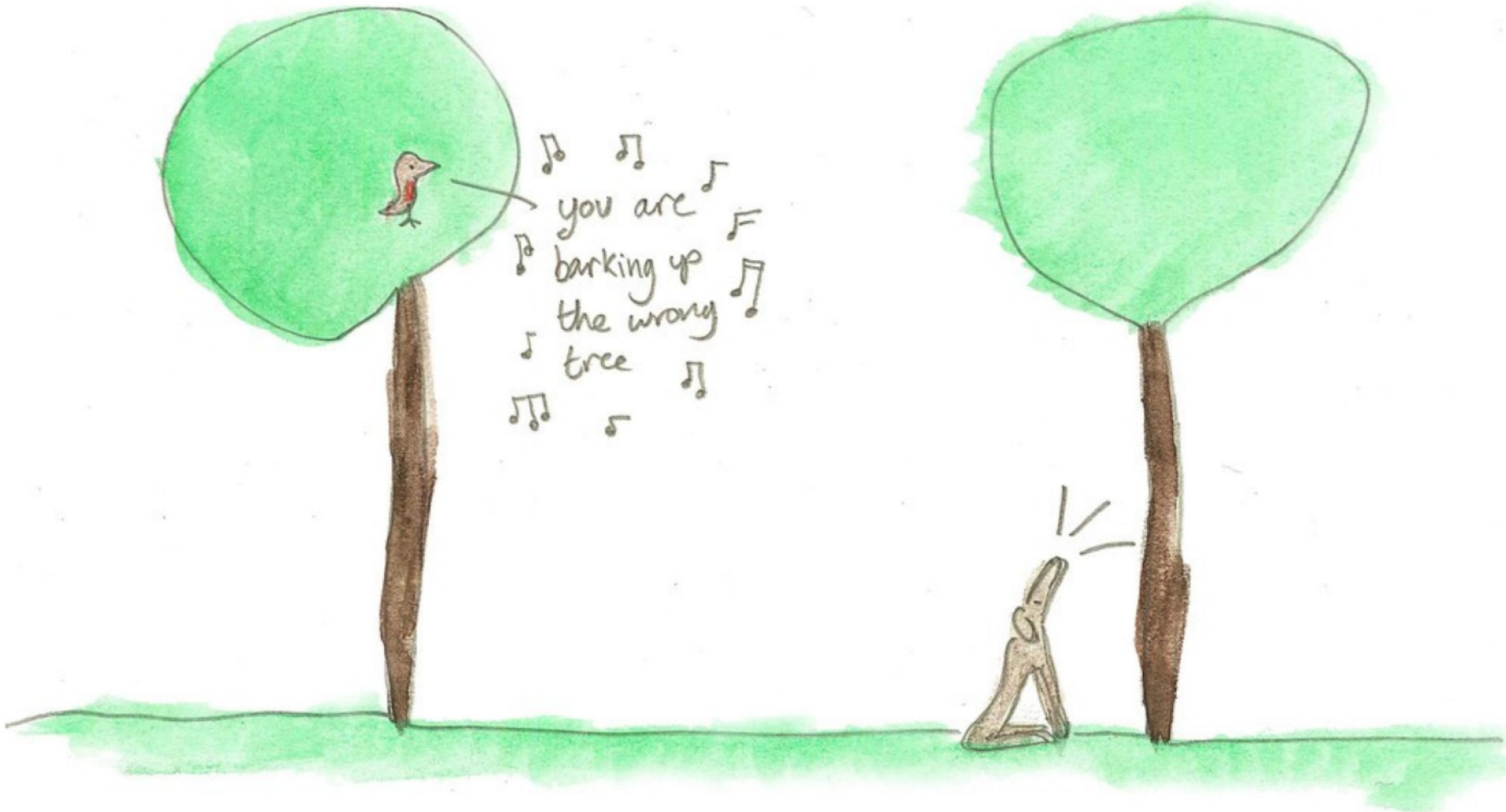
What is often unknown:

- 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



What do you mean by „targeted advocacy“?



Know your trees – and bark up the right one



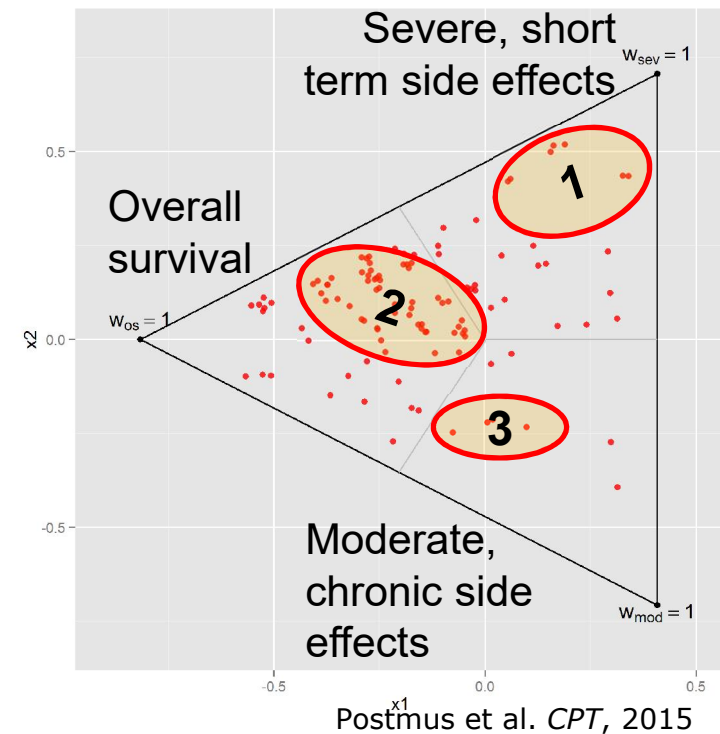
~~Somebody should do something about this!~~

- „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



What do you mean by „the right packaging“?

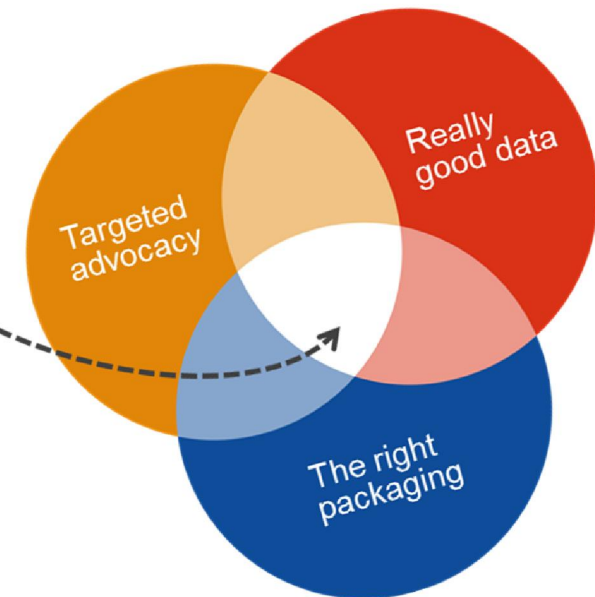


Banging your head against the wall may not be the best way getting your message across

Negotiation tactics and building your case

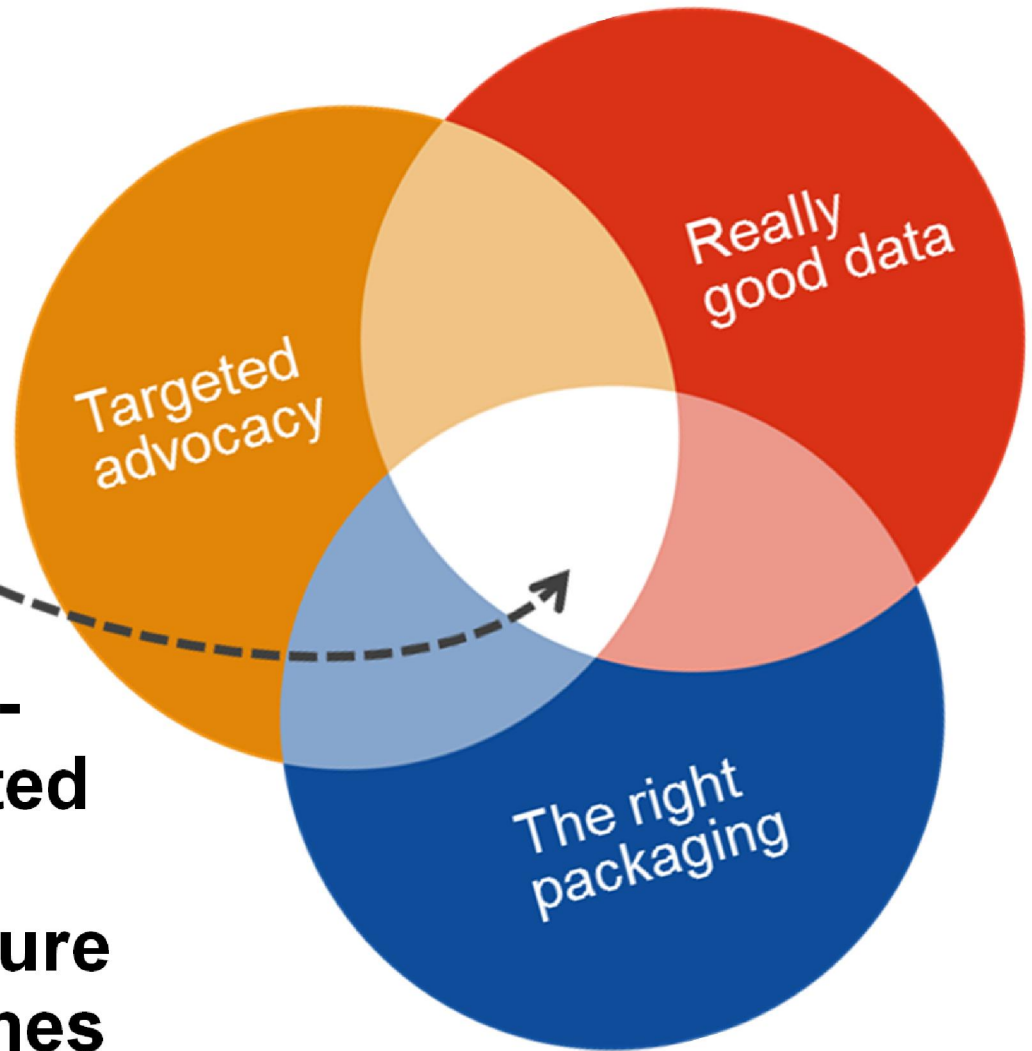


- 1 • Define the outcome and a possible retreat outcome
- 2 • Consider the second position, possible resistance
- 3 • Be clear with your reasoning, the benefits, the risks
- 4 • Present evidence and proof to reassure
- 5 • Make your delivery compelling
- 6 • Explore barriers and resistance with empathy
- 7 • Represent your case, ask for commitment



Evidence-based advocacy

Advocating in in a targeted, evidence-based, well-educated and professional manner, and measure impact and outcomes of what we do



**CML
HORIZONS**



**WARSAW
POLAND
4-6 MAY 2018**

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**