

# Why does the voice of patients matter in research and regulatory affairs?

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# Questions

- Why does Science matter in patient advocacy?
- How can patient advocates become partners (instead of mere study objects) in research?

# SUCCESSFUL PATIENT ADVOCACY



# The 3 knowledge pillars of effective Melanoma advocacy

## Disease

- Melanoma
- treatments
- disease management
- early detection and follow-up schemes
- genetic predisposition, risk factors and prevention

## Systems

### Healthcare

- access to Melanoma care: how does my healthcare system work?
- drug development, including regulatory, HTA and reimbursement

### Political

- decision-making in healthcare

### Research

- how does research work, how to drive specific research?

## Advocacy tools

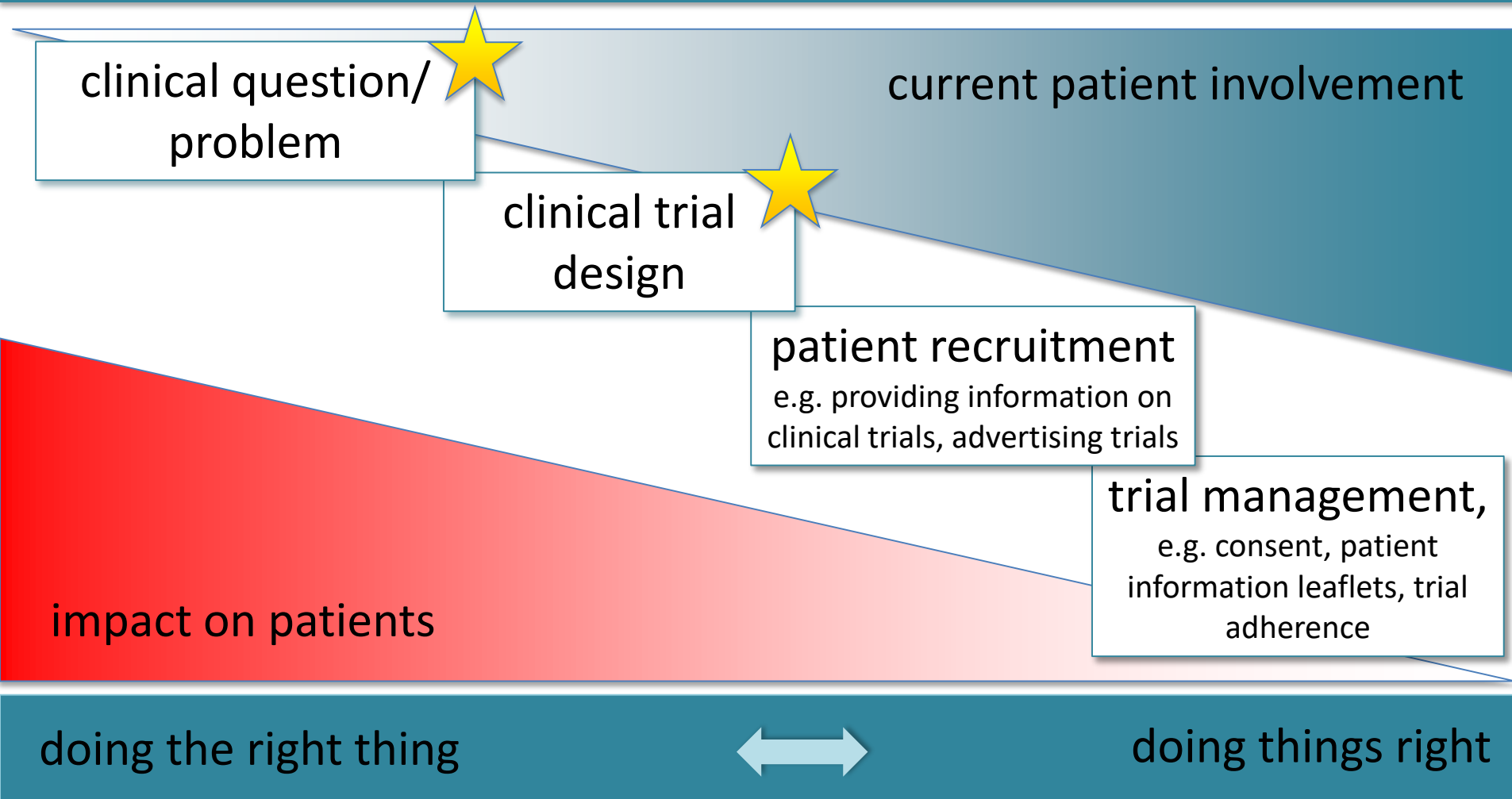
- strategy
- organisation
- communication
- finance
- governance

# **The 2 reasons** for patient advocates to get involved in Science

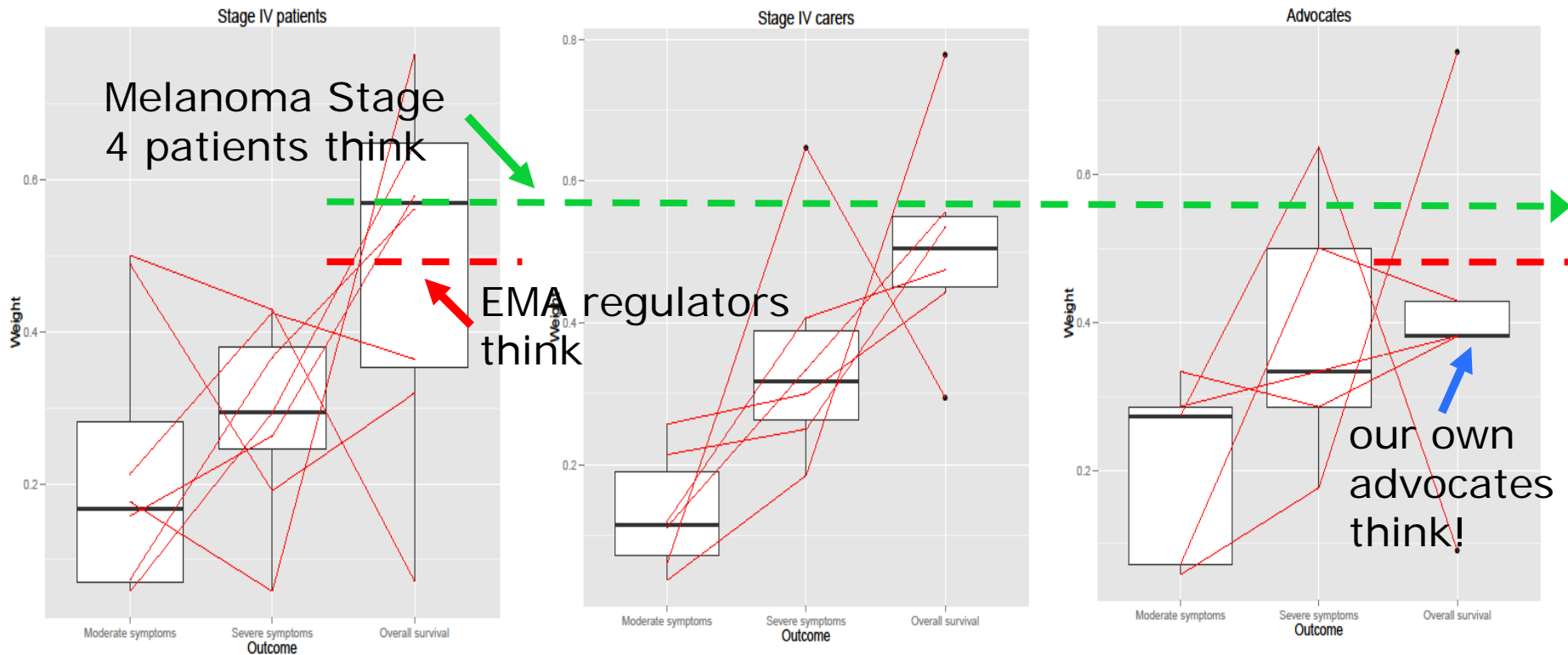
1. Science- the way it is conducted, its results and how it is reported- directly affect patients. We know that the personal experience of a disease fundamentally alters positions and priorities- just the non-patients often don't know that.
2. Science is the way to produce the evidence supporting strong advocacy claims.

engage for impact

# Where to get involved in clinical research for maximum impact★?



Melanoma Stage 4 patients don't think like their carers who don't think like advocates who are neither Stage 4 patients or carers themselves. And some are more risk-adverse than regulators!



EMA/MPNE pilot study on eliciting patient values - work in progress - commented slide.



# how to get started

# Science

Is a way of looking at the world,  
**not** a degree.

(and it's a game with rules, so if you  
want to play, get the rule book)

# Science

also-  
the art of crafty nit-picking

operates under the principle of

**FALSIFICATION.**

(If, after serious looking, we cannot find any reason why something is wrong, we consider it as correct. For right now.)

# Science for advocates

a systematic way to look at a problem.

## Methodology

*How does  
something get  
studied?*

**what to look at**

## Prioritisation

*Which topic is  
studied?*

**questions to ask**

**Are there flaws  
that mean the  
results cannot be  
trusted?**

**Does this topic  
matter to  
patients?**

# Science, how to get started

1. What is the problem/ field of interest?
2. [Pubmed](#), your new favourite website: What is already known?
3. Create one big picture of all that is known
4. Identify the gaps and whether this is in patients' interest?
5. Sparring partners are your best Science friends: Challenge your ideas and improve it continuously, try to fill the gaps

# then

6. Be part of the discussion- comment on scientific publications, discussion forums, submit opinion pieces
7. Make use of requests for support letters, invites to research committees, scientific advisory boards and research funding decisions to be constructive AND deliver what matters to patients

Thank you

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