

Drug disinvestment a physician & patient advocate perspective

13th November 2018
ISPOR

Bettina Ryll

Melanoma Patient Network Europe, Founder



Population versus individual health

- probabilities on a population level still mean binary outcomes on the individual level
- preferences for risk and benefit strongly depend on circumstances and can vary between individuals

"Would you jump out of a plane if you knew that there was a 1 in 10 chance that your parachute would not open and you would die?"

"Well, if that plane was heading towards a cliff, then yes, I would".

MPNE2015 documentary
www.youtube.com/watch?v=VlreDdQG4kc

quote from a patient
workshop, kindly provided by
M. Longley, WIHSC

B.Ryll 2018

2

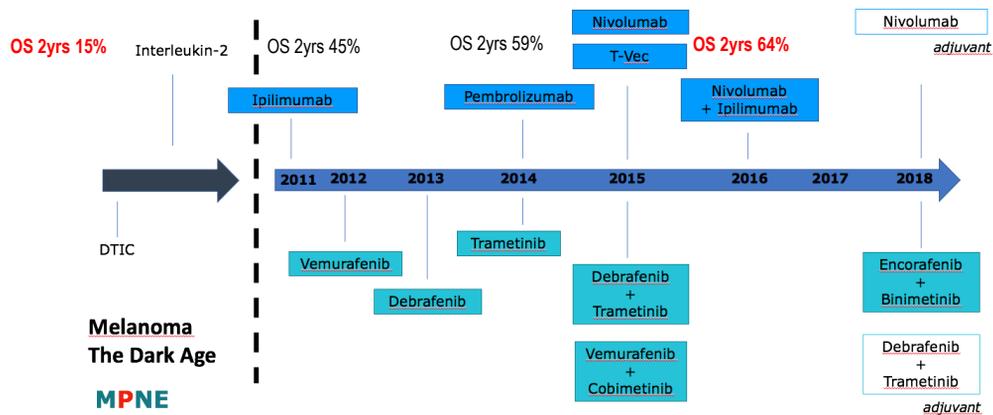
Evidence-based medicine ...

but 'don't trust any statistics you haven't faked yourself.'

B.Ryll 2018

3

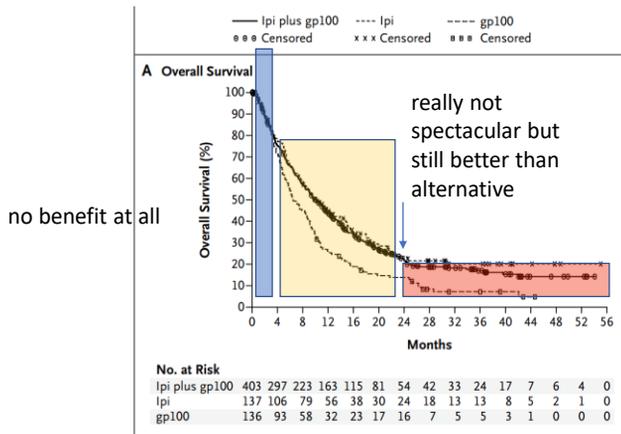
The years that changed everything in Melanoma



B.Ryll 2018

Evidence? It just depends on how you look at it

Do you want to be dead for sure or have a small chance to survive?



<https://www.nejm.org/doi/pdf/10.1056/NEJMoa1003466>

MPNE 2018

5



Any data can look good or bad

- depending on the patient population you include- a problem in times of increasingly personalised medicines
- granularity and patient-selection will become increasingly important
- evidence does not exist in an empty space- comparators and alternative options are critical *'maybe not grand but still the best we got'*
- 'the sour grape story': retro-fitting evidence to cost-constraints

➡ indiscriminate desinvestment will miss out on benefits = social cost to society

MPNE 2018

6

Trust needs to be earned....but not like this

'It is irresponsible not to check your PSA/ get your mammography- think about your families'

'It is irresponsible to check your PSA/ get your mammography- all those unnecessary follow-up exams and treatments!'

'Don't google- trust your doctor!'

B.Ryll 2018

7

to summarize

- decisions can look obvious when you talk about populations- but less so when you are the individual patient
- data on efficacy is hardly black or white, generally useless treatments tend to be underused anyway, especially in the era of guidelines = no budget impact; inappropriate generalisation leads to loss of benefit
- stop dogmatic health communication: knowledge is always limited and swinging from one dogma to the opposite without sufficient explanation (apologies would also be accepted) dangerously erodes trust

B.Ryll 2018

8

MPNE

A network for a difference in Melanoma.

www.melanomapatientnetworkEU.org

bettina.ryll@mpneurope.org