Minimal Datasets that actually matter to patients

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7th November 2017, ISPOR

disclosure

- MPNE (Melanoma Patient Network Europe) is a volunteer-based network whose activities are funded by balanced support by the following pharmaceutical companies: Amgen, BMS, Delcath, Incyte, MSD, Novartis, Roche and currently one Horizon2020 project (UMCURE). Support never includes editorial rights, influence on MPNE's program nor activities. **MPNE is strongly interested in further diversifying its funding, in particularly seeking support from regulatory and HTA bodies.**
- In the last 3 years, BR received personal consultancy fees for work in patient affairs from- Amgen, Bayer, Novartis, Merck Serono, MSD.
- BR's work for MPNE and the ESMO-PAWG is non-remunerated

what patients want

the value of normality

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you don’t know what you don’t know

until you become the patient yourself.

beware personal bias

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and I even don’t like rowing this boat

What does Quality of Life mean to you?

Research collaboration- ZIN and MPNE

“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”.

The risk of not taking risks

Trade-offs when you are diagnosed with a life-threatening disease.

quote from a patient workshop, kindly provided by M. Longley, WIHSC
MPNE2015 documentary www.youtube.com/watch?v=VIreDdQG4kc

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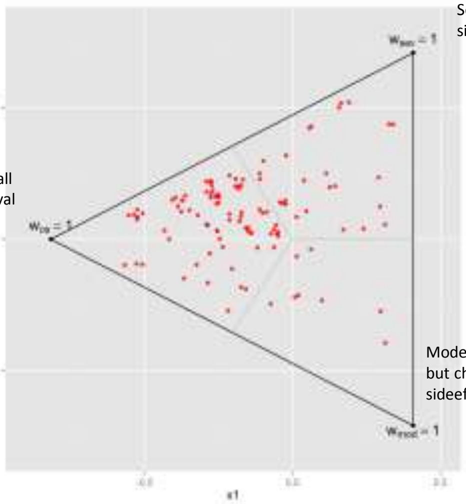
Individual preferences scatter



Severe but short-term side effects

Overall survival

Moderate but chronic sideeffects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Patient values in benefit-risk assessment

Postmus et al. CPT, 2015, Original slide by F. Pignatti, EMA, from ESMO research WS Feb 2016

BOQ vs BOD

burden of questionnaire vs burden of disease

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ROE- Return On Engagement

- In my experience, patients rather willing to share their personal experiences
- ‘Reporting’ however is usually driven by real need- side effects, care experience, looking for therapeutical options
- Most reporting tools have weak to none value propositions for patients and lack tight feed-back loops, so the reporter has limited value from reporting
- Want to increase reporting? Work on ROE for patients

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Summary

- ‘normality’ is valued highly
- beware personal projections

- patient preferences are individual
- circumstances alter risk/ benefit preferences
- patient preferences scatter naturally- and understanding granularity critical for impact

- it’s not necessarily about the volume/ frequency- it is about return on engagement for the patient

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Thank you

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