Minimal Datasets that actually matter to patients
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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

you don’t know
what you don’t know
until you become the patient yourself.
beware personal bias
and I even don’t like rowing this boat

What does Quality of Life mean to you?
The risk of not taking risks
Trade-offs when you are diagnosed with a life-threatening disease.

Individual preferences scatter

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

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

Thank you
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