



Genetic Alliance UK
Supporting. Campaigning. Uniting.

Patient Reported Outcomes Measures A Patient and Family Perspective

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Patient Reported Outcome Measures

- A good thing?
- Yes
- But not a panacea



Dimensions for a useful PROM

- Reproducible
- Valid
- Responsive to changes that matter to the patient
- Interpretable
- Acceptable (to patient and regulator)
- Feasible



Benefits from PROMs

- Capture patient experience
- Enhance recruitment/compliance
- Recognise variability of condition
- Acknowledge different/divergent realities
- Incorporate diversity
- Value carer expertise
- Secure public legitimation



Developing PROMs

- Partnership with patients/carers
- Timing – a data collection/of interpretation
- Efficient/more comprehensive use of data
- Value subjective benefits
- Acceptable to regulators (EMEA. NICE etc)
- Responsive to age, gender, cultural-linguistic and ethnic differences



An Adjunct Not a Replacement Complementary To

- Independently verifiable observations
- Bio-markers
- Physiological measures



PROMs

- Evolution not revolution
- More than political correctness or tokenism
- Tools for adding value
- Bigger bangs/research buck
- Horizontally inclusive – research with, not on



Thanks for listening

- Genetic Alliance UK
- www.geneticalliance.org.uk