

Free-text boxes pre&postworkshop questionnaires

- *I disagree considering that some children, adolescents may have a good understanding of their disease and treatment they receive but this cannot be generalized and there is I think still a high need for education and information of end users, meaning patient and parents.*
- *There is evidence that children suffering from a chronic disease have an advanced understanding about their disease and the therapies they receive. => When compared to other children of their age group or in general? In both cases I think the statement applies but more so in the first case. The extent of this statement may vary in the second case depending on the rarity of the disease*
- *More attention should also be given to how young patients participate in discussions on clinical research and specifically where their impact is to be expected. One should also discuss how advice from young patients will be received, by whom, and how it will be taken up in the design and conduct of the clinical research. The matrix appears thin and does not capture what may be of most importance.*
- *The matrix would be also helpful to decide when children and/or their carers (or both) need to be involved, in which situations children engagement is needed and recommendations on how to do it. Strategies and also a toolkit (template ICFs and assent forms for different ages and disease types) would be very useful for researchers, particularly those not involved directly in paediatric healthcare, e.g., like industry professionals.*
- *Young patients have a unique perspective and have experiences that are important for future research and drug development with the end user in mind reads attractive, but in e.g. the field of Duchenne, the subsequent regulatory aspects are not trivial, as these may impact subsequent drug development.*
- *I think it would certainly be of help to trial sponsors. Moreover, the publication of such a tool would allow citations, and increase the awareness of paediatric PPI in the first place.*
- *The current proposal is an interesting starting point but it may need further development. The matrix reflects the logic that would be followed when defining the plans for patient involvement along the development of a project. The background idea is great, so indeed, it may need further development aiming to support decision making on patient engagement.*

- *Potential use of the tool could be in many industry PE activities, and also it could be useful to provide guidance for long-term partnerships with patient groups. The tool needs to be very practical and easy to implement in industry standard procedures, ideally after a testing period that allows refinement of the tool and also adapting it to the needs of a particular stakeholder group.*