

Health State Utility Elicitation for a Rare Medical Condition

Case Study



Obtaining health utility values for rare conditions, particularly those affecting children is problematic. Because of the low prevalence and the potential ethical issues associated with approaching children, direct utility elicitation is often not possible. One solution is to use vignettes (simple, short descriptions of health states) and present these to members of the population. Time trade-off (TTO) and standard gamble (SG) approaches can then be taken, using the vignette descriptions as a basis.

YHEC was commissioned to derive utilities for a rare genetic paediatric condition affecting very young infants. To do this, YHEC designed SG and TTO vignettes corresponding to the health states reflecting different levels of severity of the condition. Participants were asked to imagine themselves as a parent of a child with this rare condition. Participants then completed the

SG and TTO. The study was conducted online, with 321 participants completing the vignettes. A clear difference was shown between the severe and least severe health states. The data were used to populate an existing economic model to support a health technology assessment submission.



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