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Estimating a Dutch Value Set for the Paediatric Preference-Based CHU9D Using a Discrete Choice Experiment with Duration

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ABSTRACT

Objective: This article presents the development of the Dutch value set for the Child Health Utility 9D, a pediatric preference-based measure of quality of life that can be used to generate quality-adjusted life-years. **Methods:** A large online survey was conducted using a discrete choice experiment including a duration attribute with adult members of the Netherlands general population (N = 1276) who were representative in terms of age, gender, marital status, employment, education, and region. Respondents were asked which of two health states they prefer, where each health state was described using the nine dimensions of the Child Health Utility 9D (worried, sad, pain, tired, annoyed, school work/homework, sleep, daily routine, able to join in activities) and duration. The data were modeled using conditional logit with robust standard errors to produce utility values for every health state described by the Child Health Utility 9D. **Results:** The majority of the dimension level coefficients were monotonic, leading to a decrease in utility as severity increases. There was, however, evidence of some logical inconsistencies, particularly for the school work/homework dimension. The value set produced was based on the ordered model and ranges from –0.568 for the worst state to 1 for the best state. **Conclusion:** The valuation of the Child Health Utility 9D using online discrete choice experiment with duration with adult members of the Dutch general population was feasible and produced a valid model for use in cost utility analysis. Normative questions are raised around the valuation of pediatric preference-based measures, including the appropriate perspective for imagining hypothetical pediatric health states.

Keywords: CHU-9D, CHU-9D-NL, discrete choice experiment, pediatric HRQoL, preference-based measures.

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Introduction

Economic evaluation of health care interventions often involves the use of incremental cost-effectiveness ratios, where the quality-adjusted life-year (QALY) is used to capture the benefit of different interventions. The QALY is a measure of benefit that captures health impact of conditions and healthcare interventions in terms of its effects on both morbidity and mortality, generated by multiplying a quality adjustment weight by duration to produce a single figure. The quality adjustment weight is often generated using an existing generic preference-based measure such as the EuroQol five-dimensional questionnaire (EQ-5D) [1] or Short-form six-dimension (SF-6D) [2,3]. These have value sets that generate utility values for all health states defined by the measure on the 1–0 full health–dead scale required to generate QALYs. These measures were developed for adults, however, and are not intended for use in children. Currently five pediatric preference-based measures are available. The EQ-5D-Y is a youth version of the EQ-5D intended for use in pediatric populations, but has no available value set to enable it to generate QALYs [4,5]. The Health Utilities Index Mark 2 (HUI2) was originally developed for use in pediatric oncology and included a fertility dimension, but is used mainly as a generic measure of health by assuming fertility is normal [6]. The Assessment of the Quality of Life-6D (AQoL-6D) can be used in pediatric populations and was derived from the adult measure [7]. The 17D is a pediatric measure and the 16D is an adolescent measure, and these were derived from the adult measure, the 15D [8,9]. The Child Health Utility 9D (CHU-9D) is a generic pediatric preference-based measure, that, unlike the other measures, has the advantage that it was specifically developed and worded for use in pediatric populations involving children throughout the development of the classification system [10–12]. Value sets exist for the United Kingdom [13] and Australia [14] enabling the measure to generate QALYs using population-specific value sets for those countries.

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Valuation of pediatric measures is a contentious issue, as there is substantial debate around who should value the measure that captures the health of children. It is a normative question as to whose values should be used to score a pediatric preference-based measure, whether it should be adults or children/adolescents. An argument for the use of child or adolescent values is that this is the group that experiences the health states (though unless they are valuing their own health, the health state will be hypothetical), and the measure is developed for completion by this group, so the values used should reflect that. However, although previous research has suggested that adolescents have understanding of some tasks, such as best–worst scaling and discrete choice experiment (DCE) [14,15], children aged 7 to 11 are unlikely to fully understand any tasks that can reasonably be used to elicit preferences for health states [16]. This raises the question of whether adolescent values are more appropriate for children (aged 7 to 11) than adult values. This is further complicated by the fact that, for ethical reasons, adolescents are usually considered unable to answer questions involving consideration of death, dying, or being dead, meaning that adult (or young adult) values are required to anchor health states on the 1–0 full health–dead scale, for example, through the use of time trade-off or standard gamble (see [17] for an overview of anchoring ordinal data onto the 1–0 scale). The practicalities of obtaining child or adolescent values anchored onto the 1–0 scale and ensuring understanding in children and adolescents participating in health state valuation present considerable challenges.

In contrast, health state valuation of hypothetical health states has been extensively undertaken using adults for a wide range of adult measures, and has been previously used to value pediatric preference-based measures (HUI2, CHU-9D, AQoL-6D). The rationale for using adult values is that because adults typically pay for health care via taxation, and are therefore the funders of the system, it is arguably their preferences that count. This is arguably also consistent with the use of general population values rather than patient values for adult health states. From a pragmatic perspective, adults presumably have a greater understanding of preference elicitation tasks used to elicit preferences for different hypothetical health states and may also be better able to imagine hypothetical health states. In addition, all preference elicitation tasks can be reasonably used in an adult population regardless of whether they mention death, for example, through asking the adult to consider whether he or she would rather be dead than live in a certain health state. However, adult preferences do not necessarily reflect child/adolescent preferences.

This article reports the valuation of the CHU-9D in the Netherlands using online DCE with duration (referred to as DCE_{TTO}, DCE time trade-off) with an adult general population sample, and presents the value set recommended for use to score the measure to generate QALYs for use in economic evaluation. This is a novel application of DCE_{TTO} that has not been used previously to value a pediatric measure. DCE_{TTO} is a relatively new technique that has been successfully used and tested to value several preference-based measures for adults (e.g., [18–23]). Respondents complete a series of choice sets including health states with an associated duration. Responses are modeled to generate a value set anchored on the 1–0 full health–dead scale required to estimate QALYs for all health states described by the classification system. In this article we also compare the new Netherlands value set to the existing CHU-9D value set for the United Kingdom.

Methods

Classification System

The CHU-9D is a pediatric preference-based measure of quality of life suitable for use in children and adolescents aged 7 to 17 years [10–12]. The measure has nine dimensions (worried, sad, pain, tired, annoyed, school work/homework, sleep, daily routine, able to join in activities), each with five severity levels (see Fig. 1). The measure was developed with qualitative interviews with more than 70 school children aged 7 to 11 in the United Kingdom. Thematic content analysis using Framework was used to analyze the data and to select both the dimensions and the wording of the dimensions [11]. The measure has been translated into seven languages including Dutch and has been used in more than 190 studies.

The measure has been valued in the United Kingdom using standard gamble on a representative sample of the adult UK general population where respondents were asked to imagine the hypothetical health state for themselves and were not informed that the health state was a description of pediatric health [13]. The measure has been valued in Australia using a representative sample of adolescents using best–worst scaling [24], where the values were anchored onto the 1–0 full health–dead scale using time trade-off values elicited from a sample of young adults [25]. An equivalent value set also exists using preferences elicited from adults [14].

The Dutch version of the CHU-9D was translated by an ISO 17100-certified translation provider, specialized in patient reported outcome measures (certificate number 3562-TX-0001). The procedure entailed concept elaboration, dual forward translation (including reconciliation), dual back translation (including a review by the CHU-9D developer), cognitive debriefing by five Dutch native speaking residents (7 to 17 years of age; either healthy or with any medical condition), and proofreading by a separate professional linguist.

Preference Elicitation Procedure

Whose values?

This study values the measure using a representative sample of the adult population in the Netherlands as also used in the UK valuation [13]. This was chosen because, first, adults are the taxpayers of the system, and second because the challenges of valuation in young children make adult valuation the most feasible approach for generating considered values.

Valuation technique

Health states have been traditionally valued using techniques such as time trade-off and standard gamble. Time trade-off determines the point at which respondents are indifferent between, say, 10 years in an impaired health state and x years ($x \leq 10$) in full health, where the health state is considered better than being dead. There are, however, well-documented issues with time trade-off and standard gamble techniques including that time trade-off can incorporate time preference and standard gamble can incorporate attitudes to risk, and both typically involve using a different process being to elicit health states worse or better than dead (see [26] for an overview). Recent years have seen increasing usage of online ordinal techniques. Best–worst scaling has been used to value health states [24,27,28], in which respondents are shown a health state with a severity level for each dimension and are typically asked to select the best part and the worst part of the health state. Best–worst scaling cannot produce utility estimates on the 1–0 full health to dead scale without the use of additional preference information about how health states are valued in relation to dead, such as through the use of time trade-off. DCE_{TTO} has been successfully used internationally to value health state classification systems such as the EQ-5D-3L, EQ-5D-5L, and SF-6D [18–23]. DCE_{TTO} has the advantage that it can be successfully used online, allowing for less costly and quicker data collection with no interviewer effect or data inputting errors. In addition, question format does not differ for

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