

Online Resource 1: Description of Data Collection Instruments

A Comparison of the Child Health Utility 9D and the Health Utilities Index for Estimating Health Utilities in Pediatric Inflammatory Bowel Disease

Running title: Health state utilities in pediatric IBD

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Description of Data Collection Instruments

This research used two generic preference-based HRQOL questionnaires to elicit health utilities in children with UC and CD: the Child Health Utility 9D (CHU9D) and Health Utilities Index (HUI). The CHU9D was developed in 2009 specifically for children and with children [1; 2]. It features a descriptive classification system of health states relevant to child health with nine dimensions: Worried, Sad, Pain, Tired, Annoyed, Schoolwork, Sleep, Daily routine, and Activities [3; 4]. Each dimension can be described by five levels. Utility weights, or tariffs, for health states described by the system were obtained from samples of Australian adults or from Australian adolescents using a best-worst scaling method [5; 6]. As part of the present research program, the validity of the CHU9D in children with IBD was previously evaluated [7].

The HUI generates health utilities using the HUI Mark 2 (HUI2) or the HUI Mark 3 (HUI3) which are multi-attribute health classification systems [8]. The HUI has been validated for use in children as young as 8 years and with parent proxies for children over 5 years. The HUI2 has 7 dimensions: Sensation, Mobility, Emotion, Cognition, Self-Care, Pain and Fertility, and the HUI3 has 8 dimensions: Vision, Hearing, Speech, Ambulation, Dexterity, Emotion, Cognition and Pain [8; 9]. The HUI2 has 3 to 5 levels of ability/disability and the HUI3 has 5 or 6 levels of ability/disability [9]. With different valuation algorithms, single and multi-attribute utilities can be calculated for the HUI2 and HUI3 using the same HUI questionnaire in children [9]. The HUI has been used in numerous patient populations and across several age groups [9], but had not been used in pediatric IBD [10].

In children with CD, the Pediatric Crohn's Disease Activity Index (PCDAI) is a standardized method of assessing disease activity [11]. The weighted Pediatric Crohn's Disease Activity Index (wPCDAI), a shorter form, has become widely accepted to assess disease activity in children with CD [11; 12]. Numerical, non-continuous scores correspond to health categories of remission (quiescent), mild, moderate and severe disease activity [11]. Similarly, the Pediatric Ulcerative Colitis Activity Index (PUCAI) is an accepted tool to assess disease activity in children with UC and categorizes UC as remission (quiescent), mild, moderate, and severe [13-15]. Both the wPCDAI and PUCAI have been well correlated with the Physician Global Assessment (PGA) [11; 15; 16]. The PGA rating is based on the physician's determination of a patient's health and unlike the PCDAI and the PUCAI, may not take into account lab values or other test results, but may be more readily attainable [11; 15]. The PGA describes disease activity as quiescent or none, mild, moderate, severe, or fulminant.

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