

Feasibility Study on the Psychometric Analysis and Qualitative Assessment of EQ-5D and Haemo-QoL-A

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Highlights

- With no mapping algorithm available between the Haemo-QoL-A and EQ-5D, the aim of this study is to evaluate the requirements to generate such an algorithm
- The level of conceptual overlap between the two measures was evaluated in a qualitative review by patient experts and health economists
- Results of the assessment suggest a level of conceptual overlap between the measures, with particular emphasis in the Haemo-QoL-A on the psychological impact of haemophilia
- This research outlines a requirement for patient data collection to facilitate the generation of a mapping algorithm

Background

- The use of cost-utility analysis by reimbursement agencies and national advisory bodies, such as the National Institute for Health and Clinical Excellence (NICE) in the UK, imposes requirements for utility data from trials
- Many trials now include a preference-based utility measure such as the EQ-5D¹ in order to compare interventions and to estimate quality-adjusted life years (QALYs)
- In the absence of data from such instruments it may be possible to map their values indirectly from a generic or disease-specific health-related quality of life (HRQoL) instrument. A number of such "algorithms" to map utilities from disease-specific measures have been published, including Crohn's disease and lower back pain^{2,3}
- Haemophilia is a genetic, life-long disorder characterised by spontaneous and post-traumatic bleeding events in the joints, muscles, and other soft tissues
- Acute symptoms of a bleed event include inflammation of the synovial fluid (synovitis), pain, and reduced mobility. Chronic synovitis arising from frequent bleed events leads to arthropathy and degeneration of the joint. The impact of both acute and chronic symptoms of haemophilia on HRQoL is well established⁴
- The Haemo-QoL-A is a disease-specific HRQoL measure used in the evaluation of adults with haemophilia.⁵ The Haemo-QoL-A has been previously validated in 221 adult haemophilia patients, showing reliability and sensitivity to changes in HRQoL and disease characteristics. Existing studies indicate congruence between the Haemo-QoL-A and EQ-5D in a cohort of patients with severe haemophilia⁵
- There is currently no mapping algorithm available to translate between the Haemo-QoL-A and EQ-5D instruments

Objective

- To qualitatively assess the level of conceptual overlap between the generic preference-based EQ-5D utility measure and the disease-specific Haemo-QoL-A, prior to development of a mapping algorithm

Method

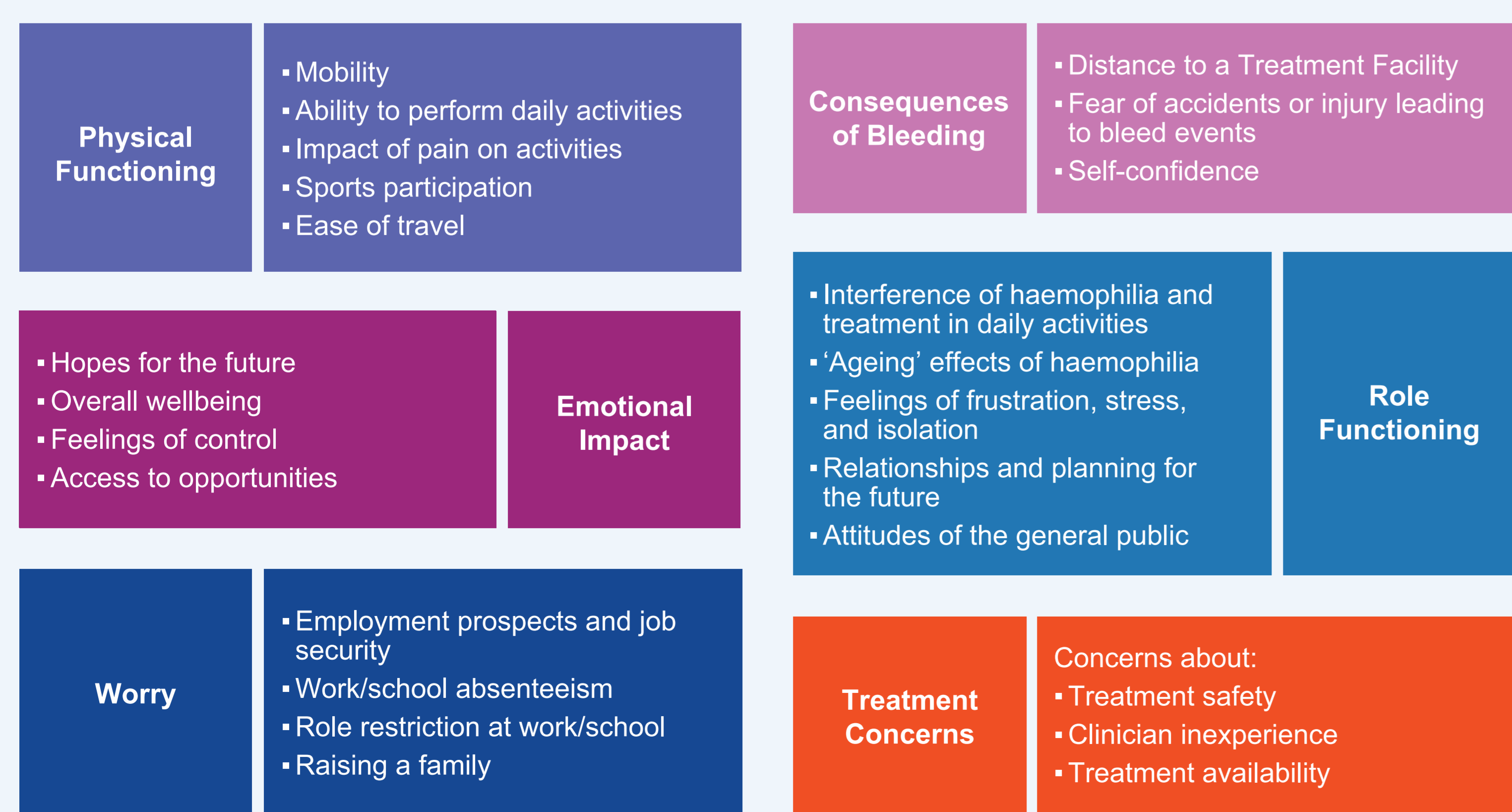
- An invited group of patient experts and health economists (N=4) reviewed the Haemo-QoL-A items and derived overarching 'themes' for each of the six subscales
- The group then assigned each of the 41 items to an appropriate EQ-5D domain, based on the theme of the item
- The level of consensus within the group was assessed; where consensus on a domain-item mapping was not reached, the most oft-selected domain was assigned

Results

Composition of the HRQoL Measures

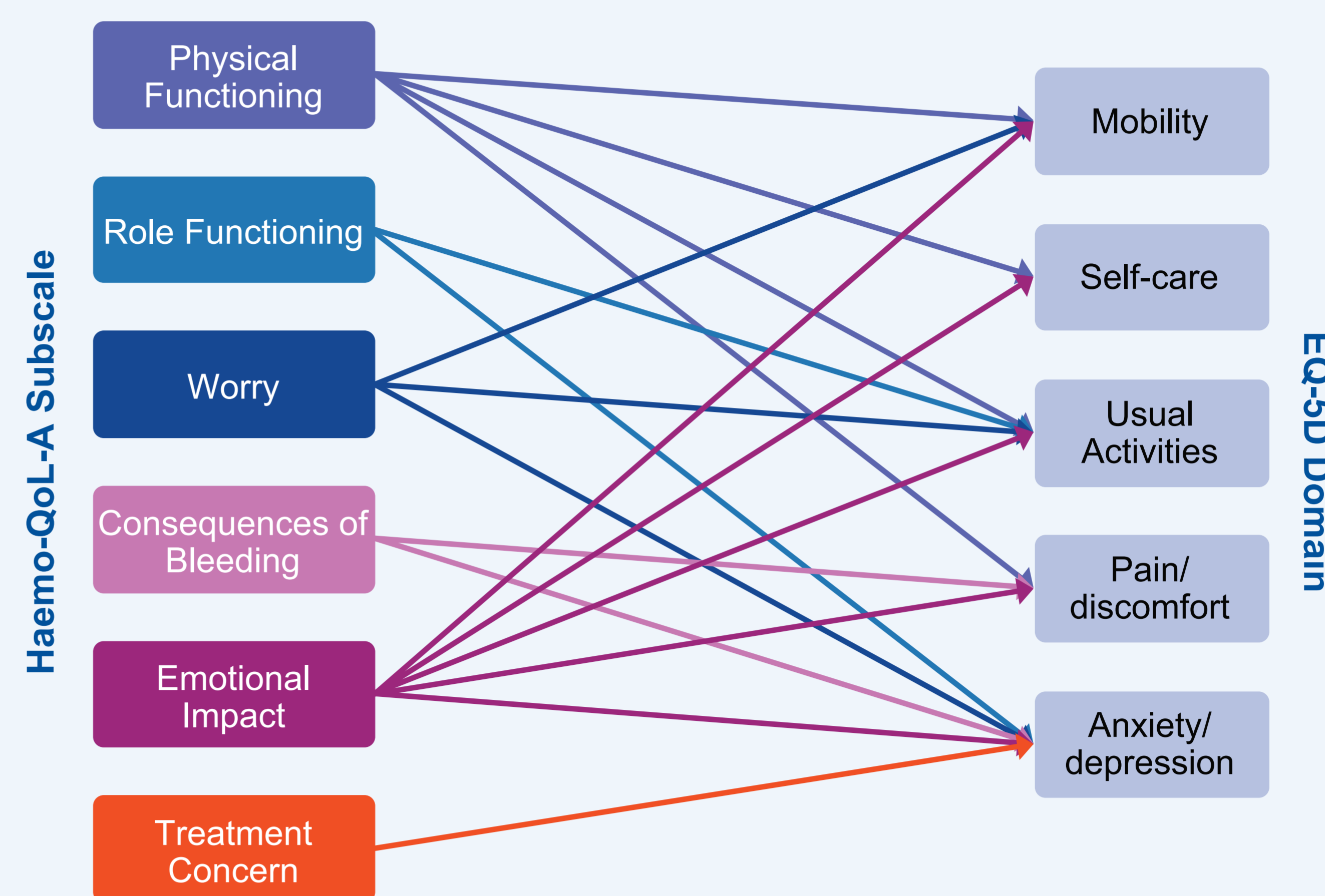
- The Haemo-QoL-A consists of 41 items pertaining to six subscales (physical functioning, role functioning, worry, consequences of bleeding, emotional impact, and treatment concern), within which are contained specific themes relating to living with haemophilia (Figure 1).⁴ The sum of the six subscales are converted to a percentage in order to generate a transformed score
- The EQ-5D tool asks five questions relating to the patient's mobility, self-care, usual activities, pain/discomfort, and anxiety/depression, followed by a global question concerning the actual health status, providing a composite utility score.¹ Responses to the five questions are given on a Likert scale of either 1-3 (EQ-5D-3L: no problems, some problems, unable/extreme problems) or 1-5 (EQ-5D-5L: no problems, slight problems, moderate problems, severe problems, and unable/extreme problems)
- EQ-5D question responses are converted into an index utility scores typically ranging between 0 and 1, with a score of 0 equivalent to death state and a score of 1 equivalent to 'perfect' health¹

Figure 1. Qualitative Themes of the Haemo-QoL-A Subscales



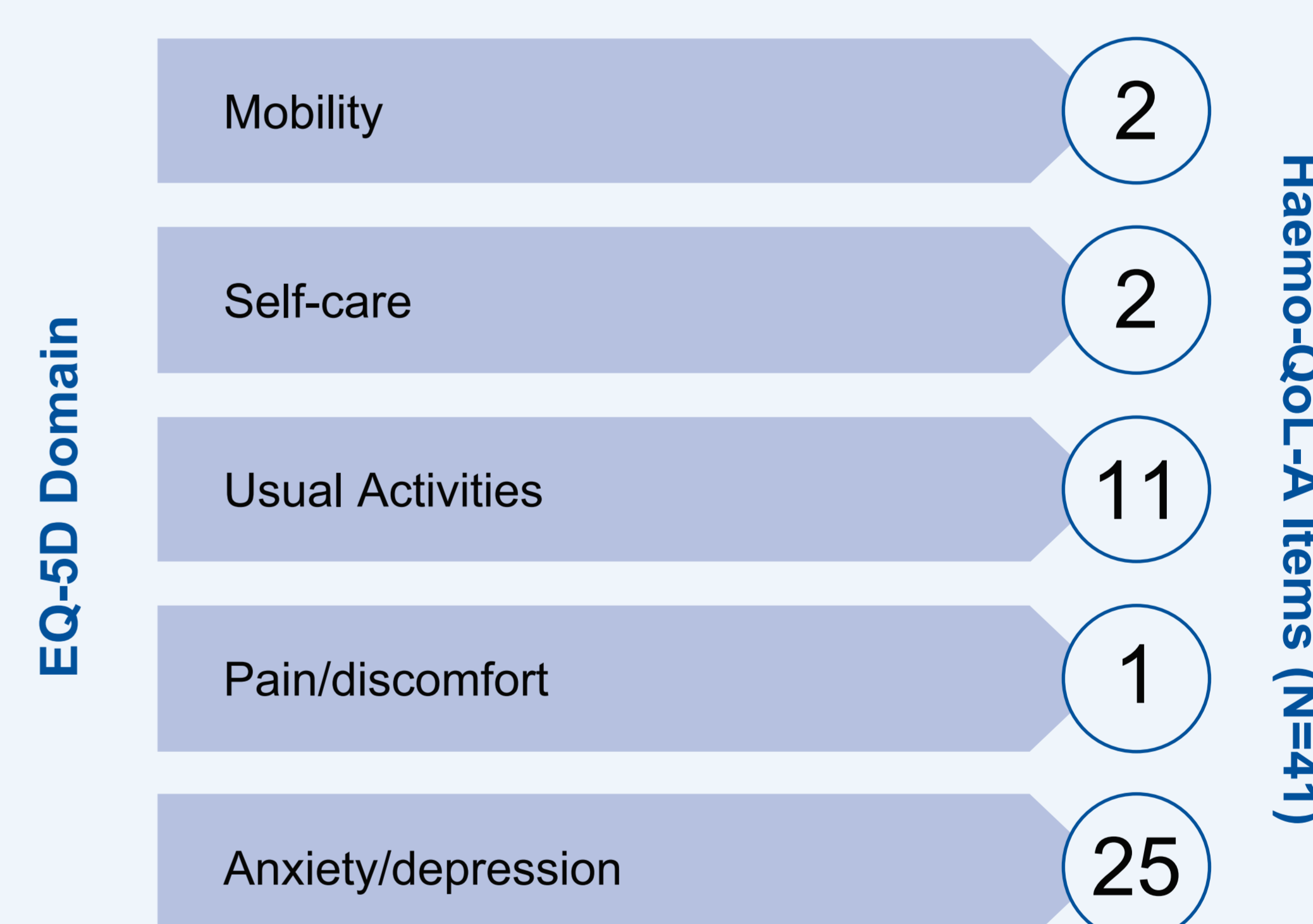
Concept Mapping Exercise

Figure 2. Relationship of EQ-5D Domains and Haemo-QoL-A Subscales



- Comparison across instruments indicated crossover in concepts from the Haemo-QoL-A to all five EQ-5D domains (Figure 2)
- The emotional impact subscale of the Haemo-QoL-A was the only subscale within which conceptual overlap with all five EQ-5D domains was observed
- Consensus in the mapping of EQ-5D domains and Haemo-QoL-A items was 59% (24 items in agreement; 17 items differed, and the dominant domain assigned)
- Both the usual activities and anxiety/depression EQ-5D domains were represented heavily in the Haemo-QoL-A (usual activities: 11 items; anxiety/depression: 25 items) (Figure 3). In particular, all items in the treatment concern subscale of the Haemo-QoL-A corresponded with the anxiety/depression EQ-5D domain
- The mobility, pain/discomfort, and self-care domains of the EQ-5D were the least-represented by the Haemo-QoL-A, with only 1 or 2 items representing an explicit conceptual overlap

Figure 3. Cross-compatibility of Haemo-QoL-A Items and EQ-5D Domains



Conclusions

- The analysis suggests a congruence between the domains of the Haemo-QoL-A and EQ-5D measures
- The Haemo-QoL-A places substantial focus on the psychosocial elements of HRQoL, such as social relationships, access to opportunities, and planning for the future. This is reflective the changing priorities in management of haemophilia patients in current clinical practice. Nevertheless, fear of bleed events and interference of haemophilia in daily activities remain as key factors in the overall level of disease-specific HRQoL
- The extent to which Haemo-QoL-A is sensitive to orthopaedic symptoms, pain, and mobility is less certain and warrants further study
- This feasibility study outlines a requirement for patient data collection to facilitate the generation of a mapping algorithm and to quantify the sensitivity of Haemo-QoL-A with respect to the EQ-5D

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Acknowledgments

BioMarin Europe Ltd. provided funding for the study, data analysis, writing, editing, and poster production. The CHES study was supported by unrestricted research grants from Swedish Orphan Biovitrum AB (Sobi) and Novo Nordisk. The study was approved by the Ethics Committee of the University of Chester, UK. The wider study was conducted in collaboration with the UK Haemophilia Society and governed by a steering committee chaired by Liz Carroll, Chief Executive of the Haemophilia Society.

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