



## Service Priorities and Programmes Electronic Presentations

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**Performance of the Upper Limb Module for Chinese Patients with Duchenne Muscular Dystrophy: a new useful clinical tool to monitor the disease progress and as an outcome measure for therapeutic drug trial**

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**Introduction**

The recent development of therapeutic treatment to Duchenne muscular dystrophy (DMD), which is a common childhood neuromuscular disorder, has highlighted the need to identify a valid and reliable outcome measures for planned clinical trials. This disease has a progressive deterioration from both lower limbs to trunk and upper limbs involvement from teenage onwards. Thus outcome measures should also be able to cover the disease spectrum from ambulatory to non-ambulatory stage. Majority of existing clinical assessment tools are targeted with walking and lower limb gross motor skills and are inadequate to serve the above purposes.

**Objectives**

Performance of the Upper Limb Module for Duchenne Muscular Dystrophy is a new tool which was found to be reliably used in both ambulant and non-ambulant patients with DMD (Marika 2014). With this study to establish the reliability in our population, this measurement tool is recently adopted for use in Chinese population of DMD in DKCH.

**Methodology**

A study was carried out to establish the reliability of this test to be used in Chinese population of DMD with ethical approval from HA HKWC Institution review board. 23 subjects with diagnosis of DMD were recruited from OP and IP in DKCH under the care of Paediatric Neuromuscular Disorder Program and Neuro-respiratory Program. There would be one session of data collection session for each participant with video recording. The performance was rated by three physiotherapists as raters individually and at one month interval. With observed good intra rater and inter rater reliability

results, PUL was then rolled out to be used as a standardized clinical tool for serial monitoring of patients' performance regarding their upper limb progress over time in DKCH.

### **Result**

There is a good intra-rater and inter-rater reliability results with ICC range from 0.85 to 0.95. Scoring obtained from PUL can satisfactorily reflect the functional decline in patients of both ambulatory and non-ambulatory stage. The pattern of decline in upper limb function corresponds well to clinical course of disease progress and can sensitively reflect functional difference upon drug treatment including chronic steroid use in clinics.

This new Upper Limb Module for Duchenne Muscular Dystrophy is a reliable and valid tool for clinical use and research purpose in Chinese population of DMD for disease and therapy monitoring.