Title **Pain poses a significant health burden in those with Joint Hypermobility Syndrome**

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Background Joint hypermobility Syndrome (JHS) is a complex multisystemic connective tissue disorder. JHS is acknowledged as a common clinical entity in musculoskeletal medicine with a prevalence of between 30%-60% in those presenting with musculoskeletal pain. It is more prevalent in females than males may present in childhood and shares symptom overlap with Ehlers-Danlos Syndrome, Marfan Syndrome and Ostegenesis Imperfecta. Patients with JHS report a variety of symptoms associated with this condition. These symptoms include: chronic pain, dislocations, impaired coordination, autonomic nervous system (ANS) and Gastrointestinal (GI) symptoms.

Aims The purpose of this study was to investigate the health burden in those with JHS and to understand which symptoms are considered to be most troublesome.

Methods A sample of 89 patients with JHS (mean age 34.6 ± 9.9 years, 82 female), diagnosed by a consultant rheumatologist according to the Brighton Criteria were compared with 113 healthy volunteers (mean age 35.7 ± 12.9, 82 female) with no musculoskeletal pain. Information relating to dislocations, ANS, GI symptoms and impaired coordination was collected by means of a self-report questionnaire. Data relating to the reporting of pain for >3 months was collected on a pain chart and the SF-12 was employed for assessing quality of life. SF-12 data is reported as Physical Component Summary (PCS) scores and Mental Component Summary (MCS) Scores. A difference in either the PCS or MCS scores of 5 points is considered to be a clinically important difference. Numerical data were analysed using independent sample t-tests and regression analysis.

Results Patients with JHS reported significantly lower mean PCS scores (M = 29.70 SD 10.63) than healthy volunteers (M = 54.45 SD 5.74), t (127.701) = 19.81, p<0.001 (2-tailed). The mean difference was 24.75 points [95%CI 22.44 - 27.06] - a statistically significant and clinically important difference. Patients with JHS were significantly more likely to report the following than healthy volunteers; subluxations/dislocations, GI and ANS symptoms and impaired coordination. The average number of pain sites reported was 10/17. Regression analysis of the reported symptoms revealed the number of pain sites as the only significant predictor of a lowered PCS score (p< 0.01) in a model explaining 23% of the variance. MCS scores of patients with JHS (M = 41.13 SD 11.60) were significantly lower than those of healthy volunteers (M = 45.64 SD 10.95), t (200) = 2.65, p<0.01. The mean difference was <5 points - this might not be clinically important.

Conclusion Patients with JHS in this study reported a statistically significant reduction in both PCS and MCS scores compared with healthy volunteers. The large difference in PCS scores is likely to be clinically important. Although multisystemic symptoms were reported multisite pain was the only symptom which contributed significantly to a lowered PCS score of the SF-12. This study high lights the health and personal burden of those with JHS and the importance of recognising and understanding the contribution of multisite pain in this population.