# A study of UK physiotherapists' knowledge and training needs in Hypermobility and Hypermobility Syndrome

### Lyell, M.J.<sup>a</sup>, Simmonds, J.V.<sup>b, c,</sup> & Deane, J.A.<sup>d</sup>

<sup>a</sup>University of Hertfordshire, School of Health and Human Social Work, Hatfield, UK.
 <sup>b</sup>University College London, Institute of Child Health, London, UK:
 <sup>c</sup>Hospital of St John and St Elizabeth, Hypermobility Unit, London, UK.

<sup>d</sup> Imperial College London, MSK Lab, School of Medicine, London, UK.

§

### Corresponding author: miranda.lyell1@btinternet.com + 44 07810137143

**Present Address:** Physiotherapy Department, Chase Farm Hospital, 127 The Ridgeway, Enfield, Middlesex, EN2 8JL.

Word count (excluding abstract = 3478)

#### Abstract

**Background:** Physiotherapists play a fundamental role in managing adults with hypermobility and hypermobility syndrome (HMS). Access to training and its influence on the physiotherapy treatment of hypermobile adults is unknown.

Objectives: The purpose of this study was to:

i) Explore UK physiotherapists' knowledge of hypermobility and HMS in adults.

ii) Establish the relationship between knowledge and training or experience.

iii) Investigate the future training preferences of physiotherapists in this area.

Design: A nationwide online survey

**Methods:** A cross-sectional survey design collected quantitative and qualitative data. A validated hypermobility questionnaire was adapted and distributed as a self - administered electronic survey. A panel of expert practitioners confirmed face validity.

**Participants:** UK physiotherapists, experienced in treating adults with musculoskeletal conditions were invited to participate via purposive and snowball sampling of relevant professional networks and clinical interest groups.

**Analysis:** Microsoft Excel and SPSS were used to analyse data. Chi-squared analysis was used to explore relevant associations. Thematic coding of qualitative data was quantitatively analysed.

**Results:** 244 Physiotherapists participated. A significant association was found between training and knowledge of HMS (P<0.001). Furthermore, training was associated with increased clinical confidence in both assessment (P<0.001), and management (P<0.001) of the condition. However, 51% of physiotherapists reported having no training in hypermobility, only 10% had undergone training in hypermobility at undergraduate level and 95% requested further training.

**Conclusion:** There are significant gaps in training received by UK physiotherapists' in the assessment and management of HMS, despite the significant association observed between training and the degree of clinical confidence and knowledge reported.

(Word count = 248 excluding title including headings)

#### Keywords: Hypermobility Syndrome, Joint Hypermobility Syndrome

#### Introduction

A joint is considered hypermobile when, taking age, gender and ethnicity into account, it moves excessively beyond its expected range [1]. Joint hypermobility can occur in an isolated area but is often widespread. This generalised hypermobility (GH) does not necessarily cause symptoms and can be an asset, allowing individuals to excel in sports or the performing arts [2]. Distinction should be made between GH and Hypermobility Syndrome (HMS), where underlying fragility of connective tissue is thought to be responsible for an array of symptoms [1]. In addition to inherited forms of hypermobility, joints can also acquire hypermobility for example, as a result of training or habitual postures [3].

GH is thought to affect 10-30% of the population, is more common in females, and decreases with aging [4]. Incidence is considered highest amongst Asian, then African populations, and lowest amongst Caucasians. Incidence seems higher in clinical populations. An observational study of new patients attending a Primary Care musculoskeletal triage clinic in London (n=150) used the Beighton Score and the Brighton Criteria to screen for GH and HMS respectively. The researchers demonstrated GH in 19% (Beighton score of 4 or more) and HMS in 30% of attendees [5]. In another study of patients attending a North London rheumatology clinic, incidence of HMS was 30% amongst males (Caucasian and non-Caucasian) and Caucasian females. The incidence doubled to 60% amongst non-Caucasian females [6].

HMS is an inherited connective tissue disorder, sharing phenotypic features with other connective tissue disorders such as Ehlers-Danlos Syndrome (EDS), Osteogenesis Imperfecta and Marfan's Syndrome [7]. Currently, HMS is believed to result from an undetermined genetic abnormality of matrix proteins and collagen within connective tissues, which results in excessive joint range of movement, tissue laxity and fragility [8]. Until recently HMS was known as benign joint hypermobility syndrome [7]. This potentially understated the

serious consequences of chronic pain and disability associated with the condition. As joint hypermobility syndrome is often considered indistinguishable from EDS hypermobility type [9], combining the two conditions under a diagnostic umbrella may enhance recognition and management [10]. There is ongoing debate over name and classification in the literature. To avoid confusion, HMS will be used as an umbrella term for these two conditions in this paper.

HMS is increasingly recognised as a multi-systemic condition, with musculoskeletal and nonarticular features. Widespread pain is common, resulting from tissue strain, dislocations or surgery [11]. Analgesia, anxiety and perceived impairment in HMS all have the potential to contribute to processing changes within the central nervous system [12]. Resultant chronic pain and kinesiophobia can lead to deconditioning and a debilitating loss of function [13]. Reduced proprioceptive acuity, particularly in lower limb joints is recognised in HMS [14]. Lack of kinaesthetic awareness and consequent adoption of unfavourable biomechanical positions, may further exacerbate pain [15].

Muscle weakness and fatigue are common features of HMS and often coexist, but their causes and relationship is not fully understood [16]. Rombaut et al. [17] demonstrated reduced muscle strength, strength/endurance and lower limb function in Caucasian females with HMS compared with age matched controls. Causes of muscle weakness found in HMS may be biomechanical failure of the extracellular matrix [18], or neuromuscular deficit [19]. Inefficient muscle action may contribute to excessive fatigue, or there may be systemic explanations perhaps linked with autonomic dysfunction [20], pain, or psychological distress, [16]. Furthermore, Chronic Fatigue Syndrome (CFS) and Fibromyalgia (FM) are conditions with overlapping features of sleep impairment, fatigue and musculoskeletal pains [21]. Sub-groups of both conditions have been described with higher incidence of joint hypermobility than in the general population [22].

Associated non-articular features of HMS have been reported. Tissue laxity potentially results in incontinence [10], asthma [23] and gastrointestinal tract dysfunction [24].

Neurophysiological traits include resistance to anaesthetics [25] and cardiovascular autonomic disturbances including orthostatic intolerance, and postural tachycardia syndrome [20]. These dysautonomias may be a primary cause of physical deconditioning or present as a secondary effect of reduced fitness [20]. Furthermore, individuals with HMS demonstrate a considerable increased risk of developing panic disorders, agoraphobia and social anxiety. A fifteen year follow-up cohort study found anxiety was twenty two times more likely amongst HMS subjects with associated use of anxiolytic drugs compared with non-hypermobile individuals [26].

Management of adults with HMS is complex and often involves multidisciplinary collaboration with physiotherapists playing a fundamental role within this team [7]. However, there is little robust evidence supporting optimum physiotherapy strategies, and a lack of clinical guidelines for the assessment and management of this multi-systemic condition. Therefore it is of interest to explore current physiotherapy knowledge and practice as this may help guide future research. This research builds on previous work undertaken in 2008, [27] in which Deane et al. designed the Hypermobility and HMS questionnaire (HHQ) to examine the baseline perceptions amongst adult musculoskeletal physiotherapists within three of the largest NHS teaching hospitals in London. Findings were that both knowledge of symptoms and the adoption of appropriate management strategies for HMS were significantly related to whether the physiotherapist had received training about the condition (P=0.05). However, 88% of those surveyed had received no undergraduate, and 60% had received no postgraduate training in HMS. A recent nationwide survey of paediatric physiotherapists (n=91) found 51% had received no training in hypermobility, [28]. The purpose of this study was therefore to investigate these themes at national level with the objectives to:

i) Explore UK physiotherapists' knowledge of hypermobility and HMS in adults.ii) Establish the relationship between knowledge and training or experience.iii) Investigate the future training preferences of physiotherapists in this area.

#### Method

#### Research design

A cross-sectional electronic survey was used to investigate views of musculoskeletal physiotherapists working within the UK.

Ethical approval was granted by the University of Hertfordshire (Ethics Committee with Delegated Authority for Health and Human Sciences).

A literature search was performed (March – June 2013) using Cinahl, Pubmed and the Cochrane databases as these were predicted to include relevant physiotherapy, rheumatology and medical literature related to the topic. A previously validated questionnaire, the HHQ [27] was revised to include demographic questions and expand the associated features and management options sections to reflect current HMS literature. A pilot study was completed to ensure face validity of the adapted instrument. Eight expert physiotherapists were invited to participate in the pilot. Expertise was defined as specialised clinical experience with this client group, publication or lecturing in the field of hypermobility. Minor modifications were made as a result of the pilot. The revised tool was named the Modified Hypermobility and Hypermobility Syndrome Questionnaire (Modified HHQ) and can be found in Appendix 1.

The survey was converted to an electronic format using Bristol Online Survey software. Questions were generally closed, generating quantitative data. Qualitative data was collected through six open-ended questions to add depth and provide insight into clinician's responses. Informed consent was gained on the initial page of the survey. Questions were mandatory, which avoided the collection of incomplete data. The exception was a question seeking views regarding treatment effectiveness. Respondents could omit this question if they felt unable to comment due to lack of experience in treating the condition.

#### Data collection

Purposive distribution targeted physiotherapists who treat adults within a musculoskeletal setting in the UK. Relevant permissions were sought allowing the questionnaire to be distributed via the iCSP, Allied Health Professions Research Network (AHPRN) and a variety of professional special interest groups who either posted it onto their websites or emailed it to their members.

Snowball sampling, a chain referral recruiting mechanism [29], boosted responses. Interested participants were asked to snowball the survey to other potential participants within their network. Pre-notification and reminders were used to enhance response rate [30]. The survey was open for six weeks between September 11<sup>th</sup> and 23<sup>rd</sup> October 2013.

#### Data analysis

Data was transferred from Bristol Online software to Microsoft Excel. Correct answers were given a point with other responses scoring zero. Descriptive statistics were used to compare knowledge scores. Data about knowledge, training, experience, assessment confidence and management confidence was assigned to categories and coded as high or low. Chi square analysis (IBM SSPS Statistics 21 software) was used to explore relevant associations between categories and establish significance levels.

Inductive content analysis was used to evaluate the qualitative data. Themes were established from the data and coded. Similar responses were assigned to broad categories in order to interpret and describe the information collected.

#### Results

#### **Demographics**

244 complete questionnaires were returned with all UK regions represented as demonstrated in Figure 1. *Insert Figure 1 here*.

The majority of questionnaires, 75% (182/244), were completed by physiotherapists working in musculoskeletal outpatients, where 48% (116/244) reported working in the NHS and 27% (66/244) in the private sector. Representation from other clinical specialities included: Rheumatology (9%), Women's Health (3%), Orthopaedics (2%), Sports (2%) and Performing Arts (1%). The remainder were non-specific clinical areas such those working in rotational posts.

#### Training in hypermobility

The majority, 94% (230/244), of respondents reported having trained as a physiotherapist in the UK; 6% (14/244) had trained overseas. Half of the respondents, 51% (124/244), had received no specific training in hypermobility. Only 10% (24/244) reported having received hypermobility training as an undergraduate, and this was highest amongst therapists who had qualified within the last five years. Most experienced therapists had undertaken hypermobility training as a postgraduate.

#### Experience

85% (209/244) of respondents reported more than 5 years of clinical experience. A summary of postgraduate experience is presented in Table 1. *Insert Table 1 here.* 

#### Knowledge

Knowledge of three broad areas was considered: general epidemiological factors, musculoskeletal and non-articular features, which were added to provide a total knowledge score with a maximum value of 32. Respondents were considered to have limited knowledge if they scored <17/32 and good knowledge if they scored  $\geq$ 17/32. The mean score was 6.86/11 (sd = 1.85) for epidemiological factors, 6.65/9 (sd = 1.47) for musculoskeletal features and 6.42/12 (sd = 3.29) for non-articular features. A summary of knowledge scores is found in Table 2. *Insert Table 2 here*.

#### Analysis

Chi square analysis was used to establish the relationship between knowledge and training, experience and confidence. A significant association was found between both knowledge (total score) and hypermobility training,  $[\chi^2(1) = 14.432, P<0.001]$  and also between knowledge and years of postgraduate experience  $[\chi^2(1) = 8.444, P<0.004]$ . Furthermore, practitioners who had received training in hypermobility (P<0.001) reported significantly increased confidence in both assessment  $[\chi^2(1) = 27.472, P<0.001]$  and management,  $[\chi^2(1) = 14.747, P<0.001]$  of HMS.

#### Future Learning

Therapists were asked about preferences for training and could indicate multiple choices. 95% (231/244) indicated an interest in pursuing training in hypermobility, requesting a range of learning materials (Figure 2). Publications, courses and CPD workshops were the main preferences. *Insert figure 2 here.* 

#### Discussion

A survey was conducted to gain insight into current knowledge of hypermobility and HMS amongst UK physiotherapists working with adults and to explore any relationship between their experience and any training they had received. A total of 244 completed surveys were returned, with representation from all UK regions. Most respondents, 85% (209/244), reported greater than five years' experience, similar to 84% in a study of paediatric physiotherapists [28]. This may reflect the sampling methods and distribution networks used. Alternatively, it may be that this complex condition is encountered or clinically recognised more often by experienced practitioners.

#### Knowledge – General

Physiotherapists generally knew most about the musculoskeletal features of HMS and least about the non-articular features. Knowledge of general epidemiological features of HMS was mixed. Most respondents, 89% (217/244), knew that it is a heritable condition, 94% (230/244)

that it affects ligaments, and 91% (222/244) that it is more common in females. Knowledge of prevalence in the general population was poor, 54% (132/244). Agreement of the ethnic dominance of hypermobility in Asian populations was low, 33% (81/244). Variations linked to ethnicity are complex [4].

Although GH can be an asset [2], it has also been suggested in the literature that it may predispose to injury, not only in sport [31] and the performing arts [32], but also amongst musculoskeletal caseloads [5,6], and therefore recognition by clinicians is important. Increased awareness may enable better screening for hypermobility during selection or assessment. Fewer than half of respondents, 48% (116/244) recognised that hypermobility could be acquired. This can occur through training, stretching or habitual end range postures. Recognition may help to protect vulnerable joints from acquiring hypermobility when the wider kinetic chain is considered during training or rehabilitation.

The ability to distinguish between GH and HMS was also limited. Despite 57% (139/244) of responses indicating there is a difference, only 28% (68/244) gave a correct definition of HMS. A common misunderstanding was that a high Beighton score determined a diagnosis of HMS. The Beighton score, although originally designed for epidemiological purposes, has been widely adopted as an assessment tool for GH. The tool has limitations with lack of consensus about the diagnostic cut-off point leading to confusion over diagnosis [4]. Furthermore, evaluation is restricted to specified joints and the severity of hypermobility is not measured. As the Beighton score fails to evaluate the associated features of HMS, the revised Brighton scoring system is the recommended alternative [7]. Training is required here. The multi-systemic presentation of HMS must be recognised by clinicians in order to tailor treatment appropriately and collaborate with multidisciplinary colleagues when required.

#### Knowledge – Musculoskeletal

Knowledge scores were higher for all musculoskeletal features than in an earlier study [27]. Many practitioners included within the sample were highly experienced in musculoskeletal

physiotherapy, which may account for the greater knowledge seen in this study, or it could reflect increased awareness of hypermobility through recent publications and training.

#### Knowledge – Associated conditions

56% (137/244) of respondents felt osteoarthritis was associated with HMS. Whether hypermobility predisposes towards osteoarthritis [33], or protects against it [34] remains unknown [4]. Further research to establish the relationship was recently recommended in a comprehensive systematic review of osteoarthritis [35].

The impact of CFS and FM was explored. Only 39% (96/244) of respondents thought HMS was related to CFS and 50% (123/244) thought it was related to FM. Literature supports association of these conditions [21, 22]. Voermans et al. [16] suggest that more than three-quarters of individuals with HMS suffer from disabling fatigue, which is also often associated with poor concentration, sleep impairment and impaired social functioning. Recognition of the overlap between these syndromes may need to be highlighted in education programmes. Future collaborative research is recommended.

#### Knowledge – Non-articular features

Respondents were least knowledgeable about non-articular features. Poor recognition of delayed healing in HMS, 48% (118/244) has an impact on expected response to treatment and duration of physiotherapeutic intervention [31]. Only 11% (26/244) of therapists were aware of the association with asthma [23], which has implications for rehabilitation.

The relationship between the physical, autonomic and psychological features of HMS in acting as drivers for the condition is of interest [26]. Dysautonomia has been cited as a cause for the anxiety features which are over-represented in HMS individuals [36]. Although well documented [20], fewer than half, 45% (109/244), of respondents recognised the association between dysautonomias and HMS. Further research and awareness is necessary.

#### Effect of training and experience

Half the respondents, 51% (124/244) reported that they had not had any training in hypermobility. A significant association was found between knowledge of HMS and both training (P<0.001) and experience (P<0.004). Furthermore, confidence of assessment and management of HMS was significantly higher where those therapists had better knowledge (P<0.001) or had received training (P<0.001). Confidence relating to assessment and management practices was not found to be associated with experience (P=0.61 and P = 0.48 respectively). Only 10% (24/244) of respondents had received training in hypermobility as undergraduates.

#### Future education and research

Findings from this study support the need for hypermobility training for UK physiotherapists. The majority, 95% (231/244), of respondents were interested in pursuing further training in HMS. Books, journals, courses and CPD workshops were the preferred learning methods chosen by respondents. This may reflect individual circumstances or learning styles. As autonomous practitioners, physiotherapists strive to apply knowledge to clinical decision making as part of a reasoning process [37]. Lack of accessible knowledge can be a limiting factor in proficient clinical reasoning [38].

Qualitative research investigating experiences of physiotherapists working in the NHS [39] concluded that undertaking CPD improves confidence as well as competence, enabling individuals to form effective therapeutic relationships with patients and other members of their teams. In other research, Petty and colleagues [40] considered the impact on physiotherapy graduates of undertaking Musculoskeletal MSc programmes in the UK. They identified three key impact domains, critical understanding of practice knowledge, patient centered practice and capability to learn in, and from, clinical practice. The most powerful experience to trigger practice change was direct observation and feedback of clinical practice by educators. The future of education in the area of hypermobility may require a combination of existing and alternative methods. This could include observational learning, and the formation of focus or

clinical interest groups. These kinds of collaborative working where professionals share their knowledge and experiences can enhance clinical practice and outcomes [41, 42].

#### Limitations of the study

Several limitations have been identified. Although test / retest reliability was high for the original questionnaire, the extent to which this was transferred to the electronic version was not tested and therefore remains unknown.

Sampling errors arose from the selection process. A recognised flaw of volunteer sampling is the inability to accurately calculate the sample frame and non-response bias [43]. The snowball sampling technique can result in over-representation of certain characteristics [29] and the networks used may have led to a sample biased towards experienced practitioners.

Best practice recommends controlling survey admission by password in order to guarantee inclusion criteria and prevent multiple entries. A limitation of the software used was the inability to check if participants had made more than one submission or met the inclusion criteria. The latter was assumed as participants were targeted through professional interest groups with controlled memberships.

Statistical testing was used to compare knowledge and training. Assumptions were made in order to perform the tests. Knowledge was considered high if participants scored 50-100%, which is an arbitrary figure. Similarly, therapists were considered experienced if they had more than five years' experience, the justification being that physiotherapists commonly specialise in a field of practice at around that time. Consequently there was a disparity in the sample size used for comparison of experience, which undoubtedly caused bias.

#### Conclusions

Physiotherapy caseloads are likely to include GH and HMS, both of which present frequently within adult clinical services.

- Hypermobility and HMS training is not widely available to UK physiotherapists.
- This study indicates that training is significantly related to clinical confidence and knowledge.
- Recognition of the non-articular features of HMS is a priority for educational programmes.
- UK physiotherapists request publications, courses and CPD workshops about hypermobility.
- Further research is needed to help inform clinical practice.

#### Acknowledgements

Ethical approval: University of Hertfordshire Ethics Committee with Delegated Authority (ECDA) for Health and Human Sciences prior to the pilot study (LMS/PG/UH/00099) Following this, an amendment was approved before commencement of the main study (aLMS/PG/UH/00099).

Sources of funding: none. Conflict of interest: none.

#### **References**

- [1] Grahame, R. What is the joint hypermobility syndrome? JHS from the cradle to the grave. In: Hakim, A.J., Keer, R. & Grahame, R. (eds.) *Hypermobility, Fibromyalgia and Chronic Pain.* Edinburgh: Churchill Livingstone; 2010. P.19-33.
- [2] Bird, H. The performing artist as an elite athlete. Rheumatology. 2009; Kep 257. 11-16. Doi: 10.1093/rheumatology.
- [3] Simmonds, J.V. & Keer, R.J. Masterclass Hypermobility and the hypermobility syndrome. *Manual Therapy*. 2007; 12: 298 – 309.
- [4] Remvig, L., Jensen, D.V. & Ward, R.C. Epidemiology of general joint hypermobility and basis for the proposed criteria for benign joint hypermobility syndrome: Review of the literature. *The Journal of Rheumatology*. 2007; 34(4): 804-809.
- [5] Connelly, E., Hakim, A., Davenport, S. & Simmonds, J. A study exploring the prevalence of Joint Hypermobility Syndrome in patients attending a musculoskeletal triage clinic. *Physiotherapy Research and Practice*. 2015; *36*: 43 – 53. DOI 10.3223/PPR-140046
- [6] Grahame, R. & Hakim, A. High prevalence of joint hypermobility syndrome in clinic referrals to a north London community hospital. *Rheumatology*. 2004; 4 (Suppliment2): 91.
- [7] Ross, J. & Grahame, R. Joint hypermobility syndrome. British Medical Journal (Overseas & Retired Doctors Edition). 2011; 342: 275 – 277.
- [8] Malfait, F., Hakim, A.J., De Paepe, A. & Grahame, R. The genetic basis of the joint hypermobility syndromes. *Rheumatology*. 2006; 45(5): 502 – 507.
- [9] Tinkle, B.T., Bird, H.A., Grahame, R., Lavallee, M., Levy, H.P. & Sillence, D. The lack of clinical distinction between the hypermobility type of Ehlers-Danlos Syndrome and the joint hypermobility syndrome (a.k.a. hypermobility syndrome). *American Journal of Medical Genetics*. 2009; 149(A): 2368-2370.
- [10] Bird, H.A. Hypermobility does it cause joint symptoms? *European Musculoskeletal Review*. 2011; *6*(1): 34-37.
- [11] Castori, M., Morlino, S., Celletti, C., Celli, M., Morrone, A., Colombi. et al. Management of pain and fatigue in the joint hypermobility syndrome (a.k.a. Ehlers-Danlos Syndrome, hypermobility type): Principles and proposal for a multidisciplinary approach. *American Journal of Medical Genetics*. 2012; 158A(8): 2055-2070.
- [12] Voermans, N.C., Knoop, H., Bleijenberg, G., van Engelen, B.G. Pain in Ehlers-Danlos Syndrome is common, severe and associated with functional impairment. *Journal of Pain and Symptom Management.* 2010; 40(3): 370-378.
- [13]Celletti, C., Castori, M., La Torre, G. & Camerota, F. Evaluation of kinesiophobia and its correlations with pain and fatigue in joint hypermobility syndrome /Ehlers-Danlos

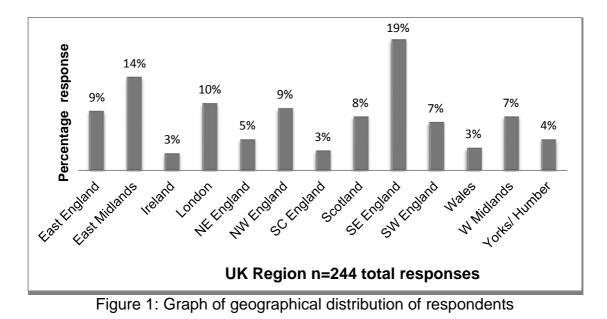
Syndrome hypermobility type. *Biomedical Research International,* (2013). Available from http://dx.doi.org/10/1155/2013/580460.

- [14] Smith, T.O., Jerman, E., Easton, V., Bacon, H., Armon, K., Poland, F. et al. Do people with benign joint hypermobility syndrome have reduced joint proprioception? A systematic review and meta – analysis. *Rheumatology International*. 2013; 3(11): 2709-2716.
- [15] Ferrell, W. R., Tennant, N., Sturrock, R.D., Ashton, L., Creed, G., Brydson, G. et al. Amelioration of symptoms by enhancement of proprioception in patients with joint hypermobility syndrome. *Arthritis & Rheumatism.* 2004; *50*(10): 3323-3328.
- [16] Voermans, N.C., Knoop, H., van de Kamp, N., Hamel, B.C., Bleijenberg, G. & van Engelen, B.G. Fatigue is a frequent and clinically relevant problem in Ehlers-Danlos Syndrome. Seminars in Arthritis and Rheumatism. 2010; 40(3): 267-274.
- [17] Rombaut, L., Malfait, F., De Wandele, I., Taes, Y., Thijs, Y., De Paepe, A. et al. Muscle mass, muscle strength, functional performance and physical impairment in women with the hypermobility type of Ehlers-Danlos Syndrome. *Arthritis Care & Research.* 2012: 64(10): 1584-1592.
- [18] Rombaut, L., Malfait, F., De Wandele, I., Mahieu, N., Thijs, Y., Segers, P., et al.
   Muscle tendon tissue properties in the hypermobility type of Ehlers-Danlos Syndrome.
   *Arthritis Care & Research.* 2012; *64*(5): 766-772.
- [19] Voermans, N.C., van Alfen, N., Pillen, S., Lammens, M., Schalkwijk, J., Machiel J. et al. Neuromuscular involvement in various types of Ehlers – Danlos syndrome. *Annals* of *Neurology*. 2009; 65(6): 687-697.
- [20] Mathias, C.J., Low, D.A., Iodice, V., Owens, A.P., Kirbis, M. & Grahame, R. Postural tachycardia syndrome – current experience and concepts. *Nature Reviews Neurology*. 2012; 8: 22-34.
- [21] Nijs, J. Generalised joint hypermobility: An issue in fibromyalgia and chronic fatigue syndrome? *Journal of Bodywork and Movement Therapies*. 2005; *9*(4): 310-317.
- [22] Nijs, J., Aerts, A. & De Meirleir, K. Generalised joint hypermobility is more common in chronic fatigue syndrome than in healthy control subjects. *Journal of Manipulative and Physiological Therapeutics*. 2006; 29(1): 32-39.
- [23] Morgan, A.W., Pearson, S.B., Davies, S., Gooi, H.C. & Bird, H.A. Asthma and airways collapse in two heritable disorders of connective tissue. *Annals of the Rheumatic Disease*. 2007; 66(10): 1369-1373.
- [24] Zarate, N., Farmer, A.D., Grahame, R., Mohammed, S.D., Knowles, C.H., Scott, S.M. et al. Unexplained gastrointestinal symptoms and joint hypermobility: Is connective tissue the missing link? *Neurogastroenterology and Motility*. 2010; 22(3): 252-262.
- [25] Hakim, A.J., Grahame, R., Norris, P. & Hopper, C. Local anaesthetic failure in joint hypermobility syndrome. *Journal of the Royal Society of Medicine.* 2005; *98:* 84-85.
- [26] Bulbena, A., Gago, J., Pailhez, G., Sperry, L., Fullana, M.A. & Vilarroya, O. Joint

hypermobility syndrome is a risk factor trait for anxiety disorders: A 15-year follow-up cohort study. *General Hospital Psychiatry*. 2011; 33: 363- 370.

- [27] Deane, J., Keer, R. & Simmonds, J. Physiotherapists' perceptions about hypermobility and Hypermobility Syndrome (HMS): a pilot survey of London based hospitals: Proceedings of *The Ninth International Federation of Orthopaedic Manipulative Therapists Conference*, 2008, 8-13 June 2008, Rotterdam, The Netherlands.
- [28] Billings, S.E., Deane, J.A., Bartholomew, J.E.M. & Simmonds, J.V. Knowledge and perceptions of joint hypermobility and joint hypermobility syndrome amongst paediatric physiotherapists. *Physiotherapy Practice and Research*. 2015; *36*(1): 33-41. Doi:10.3233/PPR-140049
- [29] Saddler, G.R., Lee, H., Lim, R.S. & Fullerton, J. Recruitment of hard to -reach population subgroups via adaptations of the snowball sampling strategy. *Nursing and Health Sciences*. 2010; *12*: 369-374.
- [30] Burns, K.E.A., Duffett, M., Kho, M.E., Meade, M.O., Adhikari, N.K.J., Sinuff, T., et al. A guide for the design and conduct of self-administered surveys of clinicians. *Canadian Medical Association Journal*. 2008; *179*(3): 245-252.
- [31] Collinge, R. & Simmonds, J.V. Hypermobility, injury rate and rehabilitation in a professional football squad – A preliminary study. *Physical Therapy in Sport.* 2009; 10(3): 91 – 96.
- [32] Scheper, M.C., de Vries, J.E., de Vos, R., Verbunt, J., Nollet, F. & Engelbert, R.H.H. Generalized joint hypermobility in professional dancers: A sign of talent or vulnerability? *Rheumatology*. 2013; *52*(4): 651-658.
- [33] Bridges, A.J., Smith, E. & Reid, J. Joint Hypermobility in adults referred to rheumatology clinics. *Annals of the Rheumatic Diseases.* 1992; *51*(6): 793-796.
- [34] Dolan, A.L., Hart, D.J., Doyle, D.V., Grahame, R. & Spector, T.D. The relationship of joint hypermobility, bone mineral density, and osteoarthritis in the general population: the Chingford Study. *The Journal of Rheumatology*. 2003; *30*(4): 799-803.
- [35] Blagojevic, M., Jinks, C., Jeffery, A. & Jordan, K.P. Risk factors for onset of osteoarthritis of the knee in older adults: A systematic review and meta- analysis. Osteoarthritis and Cartilage. 2010; 18(1): 24-33.
- [36] Gazit, Y., Nahir, A.M., Grahame, R. & Jacob, G. Dysautonomia in the joint hypermobility syndrome. *The American Journal of Medicine*. 2003; *115*(1): 33- 40.
- [37] Higgs, J. Developing Clinical Reasoning Competencies. *Physiotherapy.* 1992; *78*(8): 575 – 581.
- [38] Jones, M., Edwards, I. & Gifford, L. Conceptual models for implementing biopsychosocial theory in clinical practice. *Manual Therapy*. 2002; 7(1): 2-9.
- [39] Gunn, H. & Goding, L. Continuing professional development of physiotherapists based in community primary care trusts: a qualitative study investigating perceptions, experiences and outcomes. *Physiotherapy*. 2009; *95*(3): 210-215.

- [40] Petty, N.J., Scholes, J., & Ellis, L. The impact of a musculoskeletal masters course: developing clinical expertise. *Manual Therapy*. 2011; 16(6): 590-595.
- [41] Petty, N. & Morley, M. Clinical expertise: learning together through observed practice. *Manual Therapy.* 2009; *14*: 461 – 462.
- [42] Richardson, B. Professional knowledge and situated learning in the workplace. *Physiotherapy.* 1999; *85*(9): 467 474.
- [43] Hewson, C., Yule, P., Laurent, D. & Vogel, C. *Internet research methods a practical guide for the social and behavioural sciences*. London: Sage Publications; 2003.



	Clinical experience				
	0-2 years	3-5 years	6-9 years	10-15 years	>15 years
Number of responses	12	23	35	63	111
Percentage response	5%	9%	14%	26%	45%

Table 1: Breakdown of respondents' postgraduate clinical experience

Knowledge of:	n	Minimum Score	Maximum Score	Range Of Scores	Mean Score	Standard deviation
Epidemiology Score out of 11	244	2	11	9	6.86	1.85
Musculoskeletal features Score out of 9	244	1	9	8	6.65	1.47
Non articular features Score out of 12	244	0	12	12	6.42	3.29

Table 2. Participants' knowledge of the various aspects of HMS

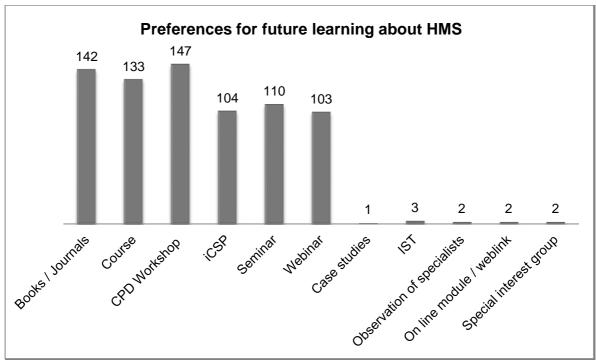


Figure 2: Respondents' preferences for future learning about HMS

## Appendix 1 The Modified HHQ

(Based on "Questionnaire: Hypermobility and Hypermobility Syndrome" by Deane, Keer & Simmonds 2008)

DEMOGRAPHICS						
Which region are you currently working in?	E England	NW England	□Wales			
	East Midlands	SC England	□W Midlands			
	Ireland	Scotland	□Yorks/			
		SE England	Humber			
	NE England	SW England				
	5	5				
How did you hear about this questionnaire?						
		From				
		Colleague	☐ Other			
	research hub	□iCSP				
In which clinical area do you predominantly work?						
		arts	⊡women's			
	(Private)	Rheumatolog	Health			
		у	Other			
TRAINING AND EDUCATION						
In which country did you graduate?	Πυκ	Other (please specify)				
How many years of postgraduate clinical experience do you have?	0-2 years	$\Box$ 6-9 years	□ >15 years			
	$\Box$ 3-5 years	□10-15 years				
Have you had any undergraduate training in (hypermobility syndrome) HMS?	□ Yes		□ No			
Have you had any postgraduate training in HMS?	□ Yes		□ No			
Are there any specialised hypermobility resources /						
facilities at your workplace?	Yes (please speci	fy)	LI No			
HYPERMOBILITY AND HYPERMOBILITY SYNDROME						
HYPERMOBILITY AND HYP How prevalent is hypermobility in the general			<u> </u>			
population?	0 – 10%	30-50%				
	□ 10-30%	└ >50%				
Could hypermobility be inherited?	□ Yes	□ No	Unsure			

Could hypermobility be acquired?	□ Yes	□ No	Unsure
Is hypermobility more prevalent in males or females?	Males	☐ Females	Unsure
In which ethnic group is hypermobility most common?	African	☐ Asian	Caucasian
Is there a difference between hypermobility and HMS?	☐ Yes	🗆 No	Unsure
What is the difference?			
Which tissue does hypermobility primarily affect?	Muscle	Ligaments	s 🗌 Skin
(Tick one)	🗆 Bone	□ Nerves	Unsure
ASSES	SMENT		
Are you confident in your assessment of hypermobility and HMS patients?	☐ Yes	□ No	
			11.100
Do you use any of the following tools when assessing in	dividuals with hype	ermobility and F	IMS?
Beighton Score	🗆 Yes	🗆 No	Never heard of it
Brighton Criteria	🗆 Yes	🗆 No	Never heard of it
Self – report (simple) questionnaire	□ Yes	🗆 No	Never heard of it
Other (please specify)			

# ASSOCIATED FEATURES

Which of the following features do you associate with HMS?						
MUSCULOSKELETAL FEATURES						
Chronic pain Dislocation / subluxation	□ Yes □ Yes	□ No □ No	Unsure	☐ Never heard of it ☐ Never heard of it		
Fibromyalgia	□ Yes			□ Never heard of it		
Laxity	🗆 Yes	🗆 No	Unsure	Never heard of it		
Osteoarthritis	□ Yes	🗆 No	Unsure	Never heard of it		
Paraesthesia	□ Yes	🗆 No	Unsure	□ Never heard of it		
Proprioceptive deficit	□ Yes	🗆 No	Unsure	□ Never heard of it		
Rheumatoid arthritis	□ Yes	🗆 No	Unsure	□ Never heard of it		
Weakness	□ Yes	🗆 No	Unsure	$\Box$ Never heard of it		
EXTRA ARTICULAR FEATURES						

Altered response to anaesthetic	🗆 Yes	🗆 No	Unsure	Never heard of it
Anxiety	☐ Yes			□ Never heard of it
Asthma	🗆 Yes	🗆 No	Unsure	$\Box$ Never heard of it
Diabetes	🗆 Yes	🗆 No	Unsure	□ Never heard of it
Delayed wound healing	🗆 Yes	🗆 No	Unsure	□ Never heard of it
Eczema	🗆 Yes	🗆 No	Unsure	□ Never heard of it
Fatigue	☐ Yes			
Gastrointestinal dysfunction	☐ Yes			_
Postural tachycardia syndrome (PoTS)	□ Yes			_
Prolapse (mitral valve, uterine, rectal)	☐ Yes			
Striae	□ Yes			_
Urinary incontinence	□ Yes			
	RELATED CO			
Is hypermo	obility related to	o any of the	e following?	
Heritable disorders of connective tissue	🗆 Yes	🗆 No	Unsure	□ Never heard of it
including Ehlers' Danlos Syndrome, Marfa	an's			
Syndrome, Osteogenesis Imperfecta?				
Pregnancy?	🗆 Yes	🗆 No	Unsure	□ Never heard of it
Chronic Fatigue Syndrome?	🗆 Yes	🗆 No	Unsure 🗌	Never heard of it
	MANAGEI	MENT		
Are you confident in your	🗆 Yes	🗆 No	1	
management of HMS?				
Does a diagnosis of HMS affect your management approach?	🗆 Yes	🗆 No	1	
Please comment				
How do you feel adults with HMS are	□ 1:1	🗆 In a	a group	□ No difference
anaged best?				between these options

If you have treated adults with HMS which modalities have you used and how effective were they?						
Acupuncture	Effective	Not very effective		Do not use		
Breathing exercises	Effective	Not very		Do not use		
Closed chain kinetic exercise	Effective	Not very effective		Do not use		
Cognitive behavioural approach	Effective	Not very effective		Do not use		
Core stability training	Effective	□Not very effective		Do not use		
Education	Effective	□Not very effective		Do not use		
Electrotherapy	Effective	□Not very effective		Do not use		
Hydrotherapy	Effective	□Not very effective		Do not use		
Intensive inpatient therapy	Effective	Not very effective		Do not use		
Manual therapy	Effective	Not very effective		Do not use		
Pelvic floor retraining	Effective	Not very effective		Do not use		
Proprioceptive training	Effective	Not very effective		Do not use		
Reassurance	Effective	Not very effective		Do not use		
Splinting / bracing	Effective	Not very effective		Do not use		
Taping	Effective	Not very effective		Do not use		
Yoga	Effective	Not very effective		Do not use		
Other (please specify)		Gilocitio				
How do you rate the impact of HMS on quality of life?	Serious	Significant	Minimal None	DUnsure		
	FUTURE	LEARNING				
Are you keen to learn more about assessment and management of adults with HMS?	☐ Yes		□ No			

How would you best like to learn?	🗆 Books / Journals	☐ Seminars		
	Courses	Webinar (online seminar)		
	CPD Workshops	Other (please specify)		
	□iCSP			
THANK YOU FOR COMPLETING THIS QUESTIONNAIRE				