Name_____Date_____ Hospital Number _____

The Spider

An impact scale for the multisystemic symptoms of patients with joint hypermobility.

This questionnaire is designed to help identify which symptoms are troubling you the most. This will help us to direct your treatment plan and monitor change.

Directions

There are 31 questions in this questionnaire. Please complete all questions.

There are no right or wrong answers. If you do not understand a question, please ask for help.

On the following page there is a list of symptoms that might be a problem for you.

Please tell us how much these symptoms have impacted your daily life during the past ONE month by marking the best suited check box. Daily life includes school and/or work, social activities, hobbies, and general tasks. This is an example:

☐ Not present	☐ No impact on daily life	☐ Mild impact on daily life	☐ Moderate impact on daily life	☐ Marked impact on daily life	☒ Disabling

Scoring

Each question is scored out of 100. The domain score is also scored out of 100 and is calculated by adding the score of each question and averaging.

Domain	Scoring
NMSK	(Q1+Q2+Q3+Q4+Q5)/5
Pain	(Q6+Q7+Q8+Q9)/4
Fatigue	(Q10+Q11+Q12)/3
Cardiac Dysautonomia	(Q13+Q14+Q15+Q16)/4
Gastrointestinal	(Q17+Q18+Q19+Q20)/4
Urogenital	(Q21+Q22+Q23+Q24+Q25)/5
Anxiety	(Q26+Q27+Q28)/3
Depression	(Q29+Q30+Q31)/3

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Neuromusculoskeletal

Symptom	Impact on daily life					
	Not present (0)	No impact (0)	Mild impact (25)	Moderate impact (50)	Marked impact (75)	Disabling (100)
1. Joint instability (e.g. subluxations, dislocations, joints feeling 'out of place', joints that are 'giving way').	☐	☐	☐	☐	☐	☐
2. Muscle weakness (e.g. Your head / limbs may feel as if they weigh too much – Your arms, hands or legs may feel weak - Your muscles may not feel strong enough)	☐	☐	☐	☐	☐	☐
3. Muscle spasms (e.g. sensation of muscle tightness, sensation of muscle contractions, …)	☐	☐	☐	☐	☐	☐
4. Problems with balance and proprioception (sensing the position of your body and limbs) (e.g. Walking into objects, tripping, falling, losing balance, difficulty in sensing where a body part is or how a joint is positioned)	☐	☐	☐	☐	☐	☐
5. Tingling sensations or loss of sensation in your limbs and / or other body areas	☐	☐	☐	☐	☐	☐

Total:

Pain

Symptom	Impact on daily life					
	Not present (0)	No impact (0)	Mild impact (25)	Moderate impact (50)	Marked impact (75)	Disabling (100)
6. Joint pain We want to know specifically about the pain in your joints. Please try to not rate pain outside the joints (such as muscle pain, radiating nerve pain).	☐	☐	☐	☐	☐	☐
7. Widespread pain in other areas of your body, such as legs, back, arms, spine …	☐	☐	☐	☐	☐	☐
8.Headaches or migraines	☐	☐	☐	☐	☐	☐
9. Pain provoked by sensations that would not be painful to most people (e.g. the pressure of clothes, someone touching you, touching the bedclothes, small movements, …)	☐	☐	☐	☐	☐	☐

Total:

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Fatigue and Sleep

Symptom	Impact on daily life					
	Not present (0)	No impact (0)	Mild impact (25)	Moderate impact (50)	Marked impact (75)	Disabling (100)
10. Feeling <u>physically tired</u> after efforts that are mild or minimal for others of your age (e.g. walking, household chores, etc.)	☐	☐	☐	☐	☐	☐
11. Feeling mentally tired after efforts that are mild or minimal for others of your age (e.g. reading, studying, talking, etc.)	☐	☐	☐	☐	☐	☐
12. Difficulty falling asleep, or difficulty staying asleep	☐	☐	☐	☐	☐	☐

Total:

Cardiac dysautonomia

Symptom	Impact on daily life					
	Not present (0)	No impact (0)	Mild impact (25)	Moderate impact (50)	Marked impact (75)	Disabling (100)
13. Feeling faint, near fainting or having a racing heart, <u>when moving to standing</u> from a sitting or lying position	☐	☐	☐	☐	☐	☐
14. Feeling faint, near fainting or having a racing heart when <u>standing upright for a long time</u> (e.g. waiting in line, on public transport, …)	☐	☐	☐	☐	☐	☐
15. In which of the situations below do you have a racing heart, feel faint or as if you are near fainting? (Check all that apply):	In warm environments (20) ☐	After a meal (20) ☐	Right after straining (e.g. during or shortly after a toilet visit, lifting heavy items, …) (20) ☐	During or right after physical activity (e.g. walking, taking stairs, cycling, …) (20) ☐	Other (20) ☐	
16. How would you rate the impact of your symptoms in these situations on your daily life, including school/work, tasks, social activities and hobbies?	☐	☐	☐	☐	☐	☐

Total:

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Gastrointestinal

Symptom	Impact on daily life					
	Not present (0)	No impact (0)	Mild impact (25)	Moderate impact (50)	Marked impact (75)	Disabling (100)
17. Abdominal bloating and/or pain	☐	☐	☐	☐	☐	☐
18. Diarrhoea and / or constipation	☐	☐	☐	☐	☐	☐
19. Nausea and/or vomiting	☐	☐	☐	☐	☐	☐
20. Reflux, regurgitation and/or difficulty swallowing	☐	☐	☐	☐	☐	☐

Total:

Urogenital

Symptom	Impact on daily life					
	Not present (0)	No impact (0)	Mild impact (25)	Moderate impact (50)	Marked impact (75)	Disabling (100)
21. Sensation of a full bladder, or a frequent urge to go to the toilet to empty the bladder	☐	☐	☐	☐	☐	☐
22. Urine loss: this may include rushing to the toilet and getting there too late, leaking urine involuntarily during activities, not feeling urine coming out or wetting the bed	☐	☐	☐	☐	☐	☐
23. Difficulty passing urine (having to push to wee) or difficulty emptying the bladder completely (the bladder does not feel empty after the toilet visit)	☐	☐	☐	☐	☐	☐
24. Unexplained genital discomfort	☐	☐	☐	☐	☐	☐
25. How often have you had suspected urinary infections over the last year? Symptoms may include: pain when having to wee, bladder pain, having to wee very often	Never (0) ☐		1-2 times (33.3) ☐	3 times (66.6) ☐		Over 3 times (100) ☐

Total:

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Anxiety

Symptom	Impact on daily life					
	Not present (0)	No impact (0)	Mild impact (25)	Moderate impact (50)	Marked impact (75)	Disabling (100)
26. Fear of moving or exercising, because of the risk of dislocations/ subluxations, pain or fatigue symptoms	☐	☐	☐	☐	☐	☐
27. Feeling worried, restless or unable to relax	☐	☐	☐	☐	☐	☐
28. Feeling afraid as if something awful might happen	☐	☐	☐	☐	☐	☐
						Total:

Depression

Symptom	Not present (0)	No impact (0)	Mild impact (25)	Moderate impact (50)	Marked impact (75)	Disabling (100)
29. Feeling down, sad, or hopeless	☐	☐	☐	☐	☐	☐
30. Feeling as though there are no solutions to your health problems	☐	☐	☐	☐	☐	☐
31. Little interest or pleasure in doing things	☐	☐	☐	☐	☐	☐
						Total:

Domain scores

Domain	**Total:**	**Average:**
NMSK		Total/5:
Pain		Total/4:
Fatigue		Total/3:
Gastrointestinal		Total/4:
Cardiac Dysautonomia		Total/4:
Urogenital		Total/5:
Anxiety		Total/3:
Depression		Total/3:

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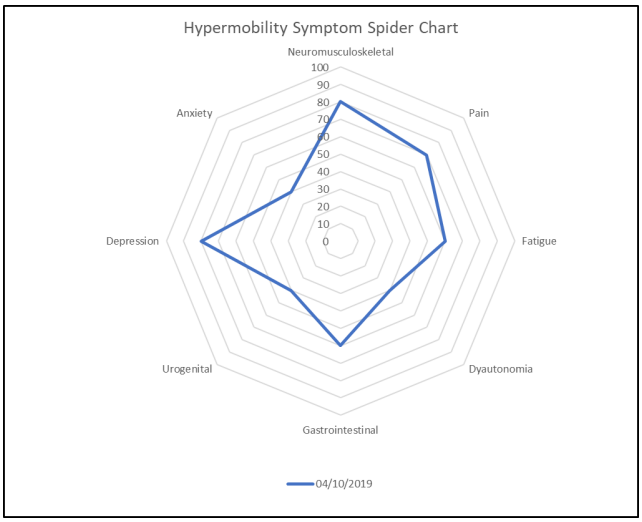
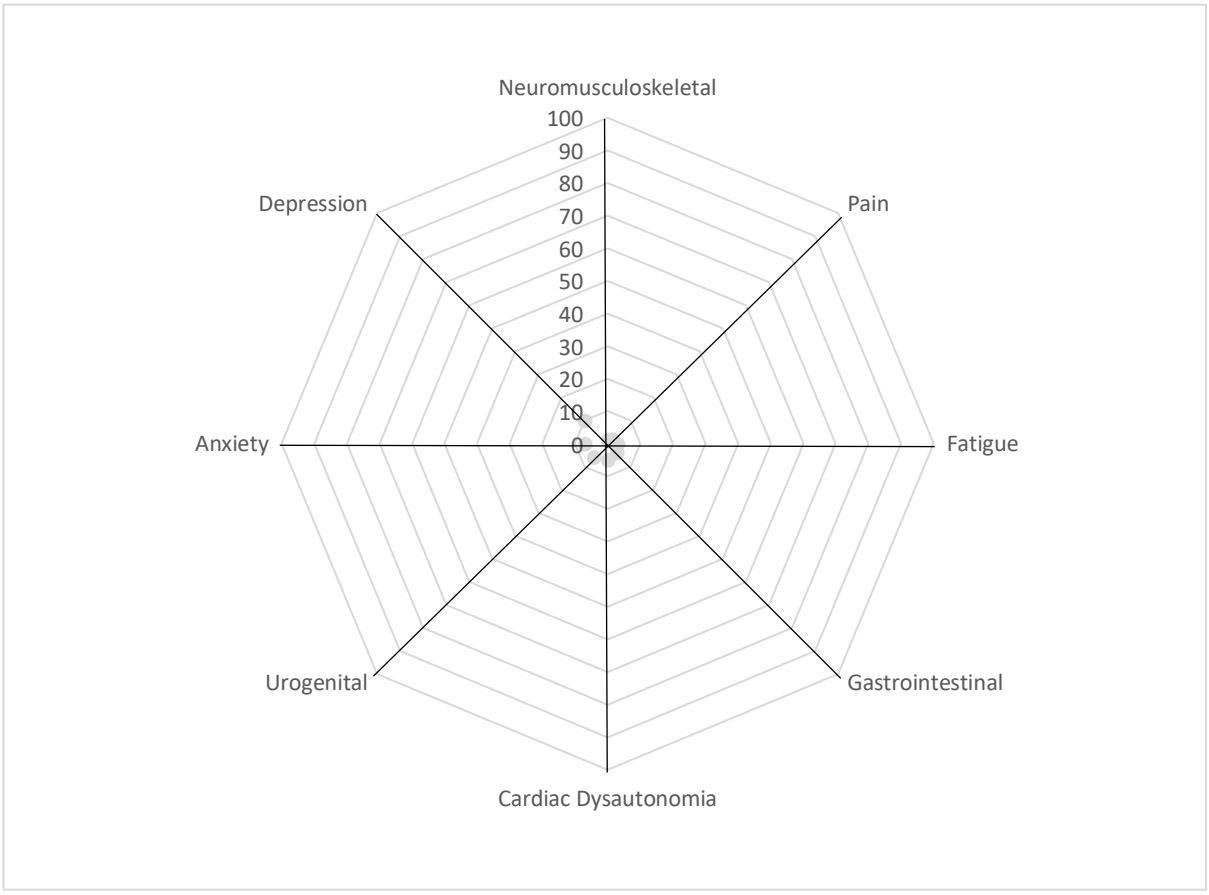
Part Two

Reflect on your responses to part one. For each leg of the spider chart below, **mark your perception** of how each symptom domain has impacted on your quality of life over the **past month**. The **greater the impact the further towards the out edge** of the spider (see example)



Mark on the diagram below how much you feel your symptoms have affected you in the past month.



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Now add the scores from each domain of the questionnaire to the below diagram.