

## **INFORMATION SHEET FOR PARTICIPANTS**

### **Exploring the knowledge, assessment and management of symptomatic hypermobility in adults among allied health professionals in the UK. A national survey using the Modified HHQ (Version 4.0)**

We would like to invite you to participate in this research project.

Before you decide, it is important for you to understand why this research is being done and what it will involve. Please take some time to read the following information carefully and discuss it with others as you wish; please feel free to ask us if there is anything that is unclear or if you would like additional information that you deem important.

If you decide to take part, consent will be gained at the beginning of the questionnaire acknowledging you agree to participate and understand what this study is about. You are free to withdraw at any time without giving a reason and without prejudice.

#### **What is the purpose of the study?**

In 2017, a new international Classification of Ehlers-Danlos Syndromes (EDS) was implemented, defining not only the different types of EDS, but also the concepts of joint hypermobility and hypermobility spectrum disorders. Within the last decade, the assessment and management of EDS and other connective tissue disorders within the UK have improved considerably thanks to the overall contributions of all allied health professions.

With these premises in mind, the purpose of this study is to explore the current knowledge, assessment, and management of all allied health professions in the UK regarding hypermobility spectrum disorders. This study will also serve as a starting point to:

- Create awareness and determine whether further education is required in undergraduate and postgraduate studies around the topic.
- Create the basis for further research exploring the best management approach for hypermobility patients from the perspective of all allied health professions.
- Provide knowledge of how other health professions manage patients to expand on referral pathways for those living with the conditions.

#### **Who have we asked to participate?**

Registered allied health professionals that are currently practising in the UK.

### When and where will the study take place?

The study requires engagement with an updated version of the Hypermobility and Hypermobility Syndrome Questionnaire (HHQ) on any device with internet connectivity.

### How long will it take to complete the questionnaire?

The questionnaire will take around 10-15 minutes to complete.

### What will happen if I take part?

Participants will be directed to the online questionnaire via a hyperlink included in the invitation email or via Social Media. The first part consists of a consent process that will give participants access to the questions once agreement is provided. A series of sections will follow, including demographics of the participants, knowledge, assessment and management of hypermobility spectrum disorders, and some questions about future learning. The data will be kept confidential and anonymous. If you decide to withdraw at any time during the completion of the questionnaire, you can simply close the questionnaire within the browser window, and your answers will not be submitted.

### Are there any risks involved in participated?

There are no anticipated risks from engaging with this research. The study has been approved by the Research Ethics Committee of the European School of Osteopathy.

### What if there is a problem or complaint?

If there is a problem at any time and you would like to contact someone regarding the study, then your contact should be:

	Name	University Address	Contact Information
Principle Investigator	Austyn Hall	European School of Osteopathy, Boxley House, The Street Boxley, Boxley, Maidstone, Kent, ME14 3DZ	austynhall@eso.ac.uk

If you have any complaint or you would like to discuss an element of the study with an independent party, your contact should be:

	Name	University Address	Contact Information
Head of Research & Professional Development	Dr Philip Bright	European School of Osteopathy, Boxley House, The Street Boxley, Boxley, Maidstone, Kent, ME14 3DZ	philbright@eso.ac.uk