

Stickler syndrome
Hypermobility Spectrum Disorder

the Ehlers Danlos syndromes
Osteogenesis Imperfecta
Marfan syndrome

Hypermobility Syndromes Project Toolkit

A local Healthwatch Project across Yorkshire and the Humber led by Healthwatch Calderdale

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Project Background

Observations gathered by a Healthwatch Advisor at a Management and Wellbeing conference in September 2017 run by the UK charities, Hypermobility Syndromes Association (HMSA) and Ehlers Danlos Support UK (EDS UK), highlighted that health services for people with hypermobility syndromes are often fragmented with no clear pathway available. People reported that medical professionals often lacked knowledge about the conditions, resulting in delayed diagnosis for many, a lack of access to appropriate treatments and poor healthcare experiences. Similar observations were collected in October 2017 at Northern Patient Day run by charity Postural Tachycardia UK (PoTS UK) and EDS UK.

So What is Hypermobility?

Hypermobility is the term used to describe the ability to move joints beyond the normal range of movement. Have a look at the photos showing hypermobility below:

Here is a bendy thumb...



An elbow:



And some knees:



Joint hypermobility is common in the general population, especially in childhood and adolescence, in females, and in people of Asian and African-Caribbean descent. In many people joint hypermobility doesn't cause symptoms. It can even be a bonus, especially for the sportsmen and women among us.

HOWEVER

Our project is NEITHER about athletes NOR party tricks. **It's about hypermobility linked to chronic ill-health. People who experience hypermobility with symptoms can be described as having a hypermobility syndrome.**

What are the Hypermobility Syndromes?

Stickler syndrome
Hypermobility Spectrum Disorder
the Ehlers Danlos syndromes
Osteogenesis Imperfecta
Marfan syndrome

Hypermobility syndromes are complex conditions, which as well as having problematic hypermobility in common, can cause many chronic health issues such as problems with blood pressure, the bowel, the bladder, temperature control, allergies, the brain and spine.

brain and spine problems
fragile skin
bladder problems
fast heart rate
allergies
joint problems
cardiovascular problems
dental and mouth problems
mental ill health
voice issues
dizziness
bowel issues

Hypermobility syndromes require a whole host of different health professionals for their diagnosis, treatment and management. The most common of the hypermobility syndromes is Hypermobility Spectrum Disorder (HSD). Other conditions of hypermobility include heritable disorders of connective tissue such as the Ehlers-Danlos syndromes, Marfan syndrome, osteogenesis imperfecta and Stickler syndrome.

Hypermobility syndromes are thought to be widespread though there is no up-to-date information regarding the exact frequency in which they occur. Hypermobility is often misdiagnosed for fibromyalgia, osteoarthritis, depression and chronic fatigue syndrome.

What do you need to do?

The good news is that you don't need to do much to contribute to our project.

Participants will access the survey online in Survey Monkey using the Internet link below:
<https://www.surveymonkey.co.uk/r/hypermobility>

By using Survey Monkey, we can collect all the data in one place. Healthwatch Calderdale and Healthwatch Leeds will analyse the data and write up the project report and case studies.

We anticipate that most participants will be able to fill in the survey online. For participants who are unable to fill out the survey online, we are advising they contact their local Healthwatch to give their survey answers over the phone. Please be prepared to do this. Answers can be directly inputted into Survey Monkey via the link above or can be taken on paper. We ask that local Healthwatch take responsibility for inputting any paper surveys from their area into Survey Monkey.

For your Website

Link to page on the Healthwatch Calderdale website which provides all the background information on the project

<https://www.healthwatchcalderdale.co.uk/our-work-4/hypermobility-syndromes-project/>

Short film introducing the project. See attachment sent along with this toolkit

For your Twitter

Below are some ready-made tweets for you to post into your Twitter feeds.

All you need to do is copy the information below and paste it into your feed.

Have you been diagnosed with a hypermobility syndrome? Tell us about your NHS and social care experiences

<https://www.surveymonkey.co.uk/r/hypermobility>

Have you been diagnosed with a hypermobility syndrome? Your input into this survey may help services understand and work with you

<https://www.surveymonkey.co.uk/r/hypermobility>

Do you think you have a hypermobility syndrome? Your input into this survey may help services understand and work with you

<https://www.surveymonkey.co.uk/r/hypermobility>

Living with a hypermobility syndrome? Your feedback may help improve services in the future

<https://www.surveymonkey.co.uk/r/hypermobility>

Think you have a hypermobility syndrome but have not received a formal diagnosis? Your feedback may help improve services in the future

<https://www.surveymonkey.co.uk/r/hypermobility>

Hashtags to use:

#EDS

#Hypermobility

#chronicpain

#Yorkshire

#fibromyalgia

#marfan

#stickler

#fibro

For your Facebook

Short film introducing the project. See attachment sent along with this toolkit.

And this post below:

We want to get a better idea of the health and social care experiences of adults with hypermobility syndromes in Yorkshire and the Humber.

If you live in this area and are an adult with a hypermobility syndrome, please fill in our survey:

<https://www.surveymonkey.co.uk/r/hypermobility>

You don't need a formal diagnosis to take part in our project. We will report on these experiences, sharing our findings with the NHS and social care service providers that we all use.

We want to build a clearer picture of the health and social care experiences of adults with hypermobility syndromes using your feedback to hopefully improve services and our experiences.

If you would find it easier to provide the information to someone in a telephone interview, please get in touch with us

Email to groups of interest

*“Dear *****

We want to get a better idea of the health and social care experiences of adults with hypermobility syndromes in Yorkshire and the Humber.

If you live in this area and are an adult with a hypermobility syndrome, please fill in our survey:

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You don't need a formal diagnosis to take part in our project. We will report on these experiences, sharing our findings with the NHS and social care service providers that we all use.

We want to build a clearer picture of the health and social care experiences of adults with hypermobility syndromes using your feedback to hopefully improve services and our experiences.

If you would find it easier to provide the information to someone in a telephone interview, please get in touch with us your local Yorkshire/Humber Healthwatch:

Healthwatch Barnsley: 01226 320106

Healthwatch Bradford: 0300 56 10 987 or 01535 665 258

Healthwatch Calderdale: 01422 399433

Healthwatch Doncaster: 0808 8010 391

Healthwatch East Riding of Yorkshire: 01482 334 999 or 01482 665 684

Healthwatch Kingston upon Hull: 01482 499038

Healthwatch Kirklees: 01924 450379

Healthwatch Leeds: 0113 898 0035

Healthwatch North Lincolnshire: 01724 844986

Healthwatch North East Lincolnshire: 01472 361 459

Healthwatch North Yorkshire: 01904 683802

Healthwatch Rotherham: 01709 717130

Healthwatch Sheffield: 0114 253 6688

Healthwatch Wakefield: 01924 787 379

Healthwatch York: 01904 621133

Healthwatch is the independent champion for people who use health and social care services. We operate at a local level as independent organisations”

Timeline

- 1st August 2018. Survey goes live
- 31st October 2018. Survey to close
- Week 3 October 2018 - begin looking at questionnaire data
- Early December 2018 - give basic feedback to organisations which contributed to engagement
- Late January/February 2019 - reports to be published (basic report for all eyes, more complex report for Healthwatch England, West Yorkshire findings report)

Many thanks to you all for working with us on this project.