

## Our conclusion

The key overarching findings from the engagement are that:

### Current NHS care

- People with hypermobility syndromes are experiencing difficulties obtaining a diagnosis. Medical professionals are frequently not recognising that the complex and multifaceted symptoms being reported are linked and for many people this leads to significant delays, often spanning years, in the diagnosis of a hypermobility syndrome.
- Some people with undiagnosed hypermobility syndromes are inappropriately referred to mental health services when medical professionals cannot find a physical cause for their symptoms.
- People experienced multiple referrals, inappropriate referrals and difficulty persuading their GPs to refer them to consultants, lengthy waiting times both pre-and post-diagnosis and an absence of follow-up appointments. Respondents, were often unable to access NHS professionals with knowledge hypermobility syndromes/related comorbidities, outside their area, due to waiting lists for being closed to patients living outside the locality in which the service was provided. A significant amount of NHS money is wasted on inappropriate referrals, and in the case of people with undiagnosed hypermobility syndromes, exhaustive testing (blood tests, scans).
- People with hypermobility syndromes are often misdiagnosed, partially diagnosed or stereotyped notably when symptoms are considered in isolation.
- The reaction of health professionals to symptoms is mixed. Largely people encountered unhelpful and unsupportive attitudes both pre-and post-diagnosis.
- Communication between health professionals is often poor both between departments in the same service and between one medical facility and another.
- People state that there is inadequate knowledge among health professionals regarding hypermobility syndromes. GPs were specifically mentioned in this regard. Rheumatologists and physiotherapists received mixed feedback in terms of knowledge.
- Most people who responded to our survey stated that they had either no NHS care or inadequate NHS care for the hypermobility syndrome.
- Positive NHS care is dependent on having regular appointments, timely referrals, recent care, specialist knowledge and positive and supportive attitudes amongst the health professionals involved.

## Future NHS care

- In terms of what could be improved in NHS:
  - people would like there to be focus on improving the knowledge and awareness of hypermobility syndromes and the associated comorbidities (e.g. postural orthostatic tachycardia syndrome, mast cell activation syndrome) among NHS professionals. An improved knowledge of these issues among health professionals, may go some way to addressing the current issues identified by respondents (e.g. disbelief) in the way many health professionals currently respond to people with hypermobility syndromes.
  - Ongoing NHS support for example by telephone, drop in services or longer treatment programmes so that problems can be addressed soon after they have arisen would also greatly improve current NHS care for people with hypermobility syndromes. Physiotherapy and hydrotherapy were both mentioned in this regard. Alternative ways of conducting appointments such as via Skype, other conferencing/telecommunication software, or telephone would also help people with hypermobility syndromes pace their energy by removing the requirement to be physically present at the appointment.
  - Reducing waiting times for referrals for both diagnosis and treatment would also help people with hypermobility syndromes as would giving more time in appointments so that the complex nature of the problems presented by hypermobility syndromes can be understood and linked together.
  - Improved communication, coordination and information sharing between health and social care, between departments within the same hospital and between treating professionals in different hospitals would be of great benefit to people, either as part of a specialist service or simply as good practice.
  - A specialist pathway for referrals and care or at the very least a single point of contact would greatly improve the NHS care for people with hypermobility syndromes.
  - Other improvements suggested by respondents include case management and care planning.

## Social care

- The most commonly reported assistance via social care was in terms of specialist equipment to help with all areas of daily living. There was an apparent dearth of knowledge about hypermobility syndromes among social care staff and a lack of awareness on the part of the respondents in terms of what is available. Respondents reported difficulties in being able to afford the financial contribution towards their social care.

## Life impact

- People stated that their difficult NHS experiences had resulted in significant life impacts, notably the loss of employment, difficulties with or dropping out of education, problems with social relationships, the breakdown of families, financial problems, issues regarding the removal of children from families by social services. People also stated that the lack of or inappropriate NHS care had resulted in long lasting and irreversible physical problems. Challenging NHS experiences had also impacted on people's mental health whereas more positive NHS interactions resulted in more helpful feelings of vindication, being understood.

## Our recommendations and next steps

We will publish this report on the Healthwatch Calderdale website, and ask that the local Healthwatch organisations across Yorkshire and Humber, which also took part in the project publish this report on their websites.

We recommend wider dissemination of the Royal College of General Practitioners (RCGP) Ehlers-Danlos syndromes toolkit across all GP practices within the Yorkshire and Humber region:

<https://www.rcgp.org.uk/clinical-and-research/resources/toolkits/ehlers-danlos-syndromes-toolkit.aspx>

Healthwatch Calderdale will also contact Pennine GP alliance, a federation of all GP practices in Calderdale, the primary-care lead at Calderdale Clinical Commissioning Group as well as the Yorkshire and Harrogate Health and Care Partnership.

We ask that all local Healthwatch across Yorkshire and the Humber contact the following organisations in this regard:

- local primary care alliances across Yorkshire and the Humber
- relevant primary care lead/s in local Clinical Commissioning Group/s

With regard to secondary care, Healthwatch Calderdale will forward this report to the Yorkshire and Harrogate Health and Care Partnership and the West Yorkshire Association of Acute Trusts, recommending that consideration be given to increasing the awareness of hypermobility syndromes among other medical professionals, in the first instance among rheumatologists and physiotherapists but also among staff who work in the areas linked to the comorbidities of hypermobility syndromes such as gastroenterology, cardiology and immunology. Healthwatch Calderdale will also contact Calderdale and Huddersfield NHS Foundation Trust in this regard and would recommend that all local Healthwatch across Yorkshire and the Humber also contact the acute NHS hospital providers in their area.

In terms of social care, we recommend that knowledge of the symptoms and nature of hypermobility syndromes as well as its associated comorbidities be improved among social care professionals for both children and adults. We hope

that an improved knowledge of hypermobility syndromes will ensure that the needs of people with hypermobility syndromes are correctly understood by professionals conducting assessments. We also hope improved knowledge will mean that the symptoms of hypermobility syndromes in children are not mistaken for child abuse or fabricated illness, as can happen currently where a child has hypermobility syndrome. We will contact the Association of Directors of Adult Social Services (ADASS) and the Association of Directors of Children's Services (ADCS) in this regard. We will also contact our local adult physical disability social care team.

This report will also be forwarded to Healthwatch England and NHS England for comment as it is clear from the project findings that adults with hypermobility syndromes across a wide geographical area are experiencing difficulties with their NHS care. The majority of people who shared their experiences of NHS care for hypermobility syndromes with us expressed concern about their NHS care and described difficulties in accessing appropriate NHS medical services and care. These findings concur with earlier observations by Healthwatch Calderdale at national/regional conferences for people with hypermobility syndromes.

Healthwatch Calderdale will provide the project toolkit and resources for other local Healthwatch across England wishing to collect the experiences of adults with hypermobility syndromes.

This report will also be shared with the national charities for hypermobility syndrome, EDS UK, HMSA and PoTS UK. It will also be sent to Dr Emma Reinhold, GP and Clinical Champion for Ehlers-Danlos syndromes.

Healthwatch Calderdale will forward this report to its local Members of Parliament. Other Members of Parliament, outside Yorkshire and Humber, with a known interest in hypermobility syndrome will also receive the report from Healthwatch Calderdale

This report will also be forwarded to the All Party Parliamentary group on Rare, Genetic and Undiagnosed Conditions asking them to provide written comment to Healthwatch Calderdale on the report.

We recommend that the feedback included in this report is used to help design and commission better services for people with hypermobility syndromes for both the diagnosis, treatment and management of these conditions.

To summarise, the report will be sent to the following NHS and social care organisations and Members of Parliament with the following requests to be completed by the beginning of November 2019:

Organisation name	Who will make contact with the organisation?	Actions and questions	Response due date
<p>Pennine GP alliance</p> <p>Calderdale Clinical Commissioning Group (Primary Care Lead)</p> <p>Calderdale Local Medical Committee</p> <p>West Yorkshire and Harrogate Health and Care Partnership</p>	<p>Healthwatch Calderdale</p>	<p>Action: To ensure that all GPs across Calderdale are made aware of the Ehlers-Danlos syndromes toolkit produced by the Royal College of General Practitioners:</p> <p><a href="https://www.rcgp.org.uk/clinical-and-research/resources/toolkits/ehlers-danlos-syndromes-toolkit.aspx">https://www.rcgp.org.uk/clinical-and-research/resources/toolkits/ehlers-danlos-syndromes-toolkit.aspx</a></p> <p>Questions:</p> <p>How will your organisation improve the knowledge of local GPs regarding hypermobility syndromes?</p> <p>How will the feedback in this report be used to improve the delivery of care for adults with hypermobility syndromes?</p>	<p>November 2019</p>
<p>Primary care alliances (via local Healthwatch across Yorkshire and the Humber)</p> <p>Clinical Commissioning Group across Yorkshire and the Humber (Primary Care Leads)</p>	<p>Local Healthwatch across Yorkshire and Humber</p>	<p>Action: To ensure that all GPs across the region are made aware of the Ehlers-Danlos syndromes toolkit produced by the Royal College of General Practitioners:</p>	<p>November 2019</p>

		<p><a href="https://www.rcgp.org.uk/clinical-and-research/resources/toolkits/ehlers-danlos-syndromes-toolkit.aspx">https://www.rcgp.org.uk/clinical-and-research/resources/toolkits/ehlers-danlos-syndromes-toolkit.aspx</a></p> <p>Questions: how will your organisation improve the knowledge of local GPs regarding hypermobility syndromes?</p> <p>How will the feedback in this report be used to improve the delivery of care for adults with hypermobility syndromes?</p>	
<p>West Yorkshire and Harrogate Health and Care Partnership</p> <p>West Yorkshire Association of Acute Trusts</p> <p>Calderdale and Huddersfield NHS Foundation Trust</p>	Healthwatch Calderdale	<p>Action: to increase awareness hypermobility syndromes among health professionals in the first instance among rheumatologists and physiotherapists but also gastroenterologists, cardiologists and immunologists.</p> <p>Question: how will the feedback in this report improve the delivery of care for adults with hypermobility syndromes with regard to:</p> <ul style="list-style-type: none"> <li>• Process</li> <li>• Treatment and support</li> <li>• Communication between healthcare professionals</li> </ul>	November 2019
Acute hospital Trusts across Yorkshire and the Humber	Local Healthwatch across Yorkshire and Humber	Action: to increase awareness hypermobility syndromes among health professionals in the first	November 2019

		<p>instance among rheumatologists and physiotherapists but also gastroenterologists, cardiologists and immunologists.</p> <p>Question: how will the feedback in this report improve the delivery of care for adults with hypermobility syndromes with regard to:</p> <ul style="list-style-type: none"> <li>• Process</li> <li>• Treatment and support</li> <li>• Communication between healthcare professionals</li> </ul>	
Association of Directors of Adult Social Services (ADASS)	Healthwatch Calderdale	Action: to increase awareness of hypermobility syndromes among Adult Social Care professionals	November 2019
Association of Directors of Children's Services (ADCS)	Healthwatch Calderdale	Action: to increase awareness of hypermobility syndromes among Children's Social Care professionals	November 2019
Healthwatch England  NHS England	Healthwatch Calderdale	<p>Questions:</p> <p>How can Healthwatch England help Healthwatch Calderdale escalate the issues with NHS care for people with hypermobility syndromes to NHS England?</p> <p>How can Healthwatch England help raise the issues in this report at a national level?</p>	November 2019
NHS England	Healthwatch Calderdale	Question: how will the feedback included in this report be used to	November 2019

		help design and commission better services for people with hypermobility syndromes in the future?	
Members of Parliament for the Calderdale are and with a known interest in hypermobility syndromes	Healthwatch Calderdale	Question: what action will you take to ensure that the feedback in this report is used to help design and commission better services for people with hypermobility syndromes in the future?	November 2019
Members of Parliament across Yorkshire and the Humber	Local Healthwatch across Yorkshire and the Humber	Question: what action will you take to ensure that the feedback in this report is used to help design and commission better services for people with hypermobility syndromes in the future?	November 2019
All Party Parliamentary group on Rare, Genetic and Undiagnosed Conditions	Healthwatch Calderdale	Question: what action will you take to ensure that the feedback in this report is used to help design and commission better services for people with hypermobility syndromes in the future?	November 2019