

About the project - Information for parents & carers

Help us to improve care for children and young people with movement difficulties

Some children and young people have conditions like **Cerebral Palsy, Brain Injury**, or other **neuro-disabilities** that affect how their muscles work. These conditions can cause **muscle tightness or stiffness**, which can make it harder for your child to move, sit, walk, or do everyday tasks. This muscle tightness is sometimes called **hypertonia, spasticity**, or **dystonia**.

If your child finds that their muscles feel tight or hard to control, or if their body doesn't always do what they want it to do, they may have hypertonia.

The overall aim of paediatric, multidisciplinary tone management treatments is to minimise the physical difficulties that children experience, and reduce the impact that this has on their participation and quality of life.

Why Is This Project Important?

Right now, there are no consistent standards across the NHS for how children with neurological movement disorders should be treated. This means that the **care families receive can vary**, depending on for example, where they live.

We want to improve services to:

- **Make sure children and young people get the right care at the right time**, without needing to travel too far.
- **Help children and young people live their best life**, by ensuring they can access tone management treatment(s) from skilled professionals, when they need it.

What Are We Trying to Do?

Children with movement disorders may need support at different stages of life. This support often involves a **multidisciplinary team**—doctors, nurses, therapists, and other professionals—working together to manage their muscle tone and reduce the physical challenges they face.

This project aims to:

- Develop agreed standards of care across South London and South East England, so that children and their families in the region can access consistent and high-quality support

- Improve pathways of care so that children and families know what to expect and where to go for help
- Understand how different services (local GPs, hospitals, and specialist centres) can work better together to support children and their families.

To achieve this, we will be engaging with people across different levels, including doctors, nurses, allied health professionals, clinical commissioning bodies and vitally, children with neurological movement disorders and their families.

Why do we need your views?

To make these improvements, we need to **hear from parents and their children and young people**.

Parents often know their children best, and can tell us what is working and what is not. Your views will help us decide what really matters when it comes to your child's quality of life, such as being able to participate in daily activities, attend school, and spend time with family. By sharing your experiences, you can help shape services that are better designed to meet the needs of children with neurological movement disorders.

How do I take part?

You can get involved in 2 ways:

1. Complete our parent survey

If you are happy to do so, you can leave your name contact details, so that we can talk to you about your answers. This is your choice and you do not have to.

2. Take part in our future Delphi study, which is about the best ways to help manage problems with muscle tone and movement.

You can email us your contact details [here](#), if you would like to receive an invite to take part.

What is a Delphi study?

We'll show you a list of statements online and ask you to rate how much you agree, or disagree with each one. We will ask parents and professionals to share their ideas. We'll collect all the answers and you will be able to see a summary of everyone's views – but no names will be shown. We will do this a few times until most people agree on what works best.

Once the process is finished, we will check to see where there is strong agreement on what works best for managing muscle tone, and then we will share these ideas with children and families, therapists, doctors and other professionals.

Consent

If you choose to take part:

- 1) Your views will be anonymous

- 2) The information you provide us with will be treated confidentially
- 3) Any data gathered from the survey may be published or used for future research, but your name and your child's name (and any other identifying information) will not be disclosed