

Sharing Your Experience with Health Watch

One barrier identified through our advocacy work is the limited visibility of adults with cerebral palsy within the healthcare system. There is not enough data about the health and care experiences of adults with cerebral palsy. Decision-makers in health and social care often rely on this data to prioritise issues and inform decisions.

What you can do:

We would like to ask you to help us produce this data. We invite you to contact Healthwatch and share your experience with health and social care services in your area. Healthwatch is a nationwide organisation in England that represents the interests of service users in the NHS. It gathers patient experiences and shares them with the relevant NHS services, encouraging improvements for service users. Healthwatch also regularly communicates its findings to decision-makers in health and social care at national, regional and local levels. This means it may be able to raise awareness of the needs of adults with cerebral palsy with different stakeholders in the NHS.

How to share your experience with Health Watch:

Please fill out their online survey: <https://www.healthwatch.co.uk/have-your-say>

You can fill in the form more than once if you want to describe experiences with different service areas, such as GP services, hospital inpatient or outpatient care, social care, or another service issue.

Below, you will find some guidance on how to fill in the form.

Step 1: While you answer to the survey, you could ask yourself the following questions to shape your response and describe your experience:

- Do these services take your CP into consideration?
- How could these services be improved to help you manage your CP better?
- What services are missing in your area that could significantly improve your health and wellbeing? You may also want to think about services that you currently have to access privately because they are not available to you on the NHS
- How is the follow-up from your GP? Do you feel that they take your CP into consideration?
- Are there NHS services that could be beneficial for you, but that you currently cannot access? For example, have any referrals been rejected?
- Do you have access to the Community Neuro Team? If not, why not? If you do, are they offering the support that you need? Would it be beneficial to receive additional support, such as mental health support? For example, some community neuro teams offer mental health support while others do not.

Step 2: Think about how you can integrate one of our policy asks in your answer. Please find below some sample text that you may like to use.

- The implementation of an adult care pathway for cerebral palsy based on the [NICE guidelines \(NG119\)](#) could significantly improve service provision for adults with cerebral palsy. It could help me manage my condition better and reach my full potential. It would also protect other adults with cerebral palsy from having the same experience as I had. In sum, it would significantly improve the health and wellbeing outcomes of all adults with cerebral palsy in this area.
- Annual reviews performed by GPs for people living with cerebral palsy, as part of the implementation of a care pathway for adults with cerebral palsy based on the [NICE Guidelines NG119](#), would significantly improve the management of CP as a lifelong condition. They would improve my ability to manage my condition and lead to better health outcomes for all adults living with cerebral palsy in this area.
- Access to support provided by the Community Neuro Team, as part of the implementation of a care pathway for adults with cerebral palsy based on the [NICE Guidelines NG119](#), would significantly improve the management of CP as a lifelong condition. It would improve my ability to manage my condition and lead to better health and wellbeing outcomes for all adults living with cerebral palsy in this area.

Step 3: The Survey asks you: Can we stay in touch?

If you feel comfortable being contacted by Healthwatch and possibly sharing your story in the media, I recommend ticking all three boxes:

- ✓ I am happy to be contacted by Health Watch England to discuss whether my story could be used as a case study.
- ✓ I want to join Health Watch England's mailing list.
- ✓ Yes, I would like my local Health Watch to know about my submission.

Ticking all the boxes in step 3 means that your story could raise awareness beyond the NHS, reach the media, and allow you to build direct relationships with your local Healthwatch. This means that your story could have significant impact.

Step 4: Informing UP

Could you please inform me when you have submitted a reply to this survey? This will help me keep an overview of our collective advocacy efforts. Please also let me know whether you ticked the boxes under 'Can we stay in touch'.

Please let us know when Healthwatch contacts you to discuss your submission in more detail or to use your submission as a case study for the media. We at UP can support you at this stage to prepare for any further engagement and messaging.

If your story gains visibility in the media and you inform us in advance, we can use that opportunity to create visibility for UP and the needs of all adults with cerebral palsy in the UK.