

Dr Caroline Jones
Statistics Regulator, Health and Social Care Lead
Office for Statistics Regulation
Statistics House, Cardiff Road
Newport
South Wales
NP10 8XG

Dear Caroline,

I am writing to you on behalf of the Neurological Alliance, the collective voice for 80 organisations working together to make life better for millions of people in England with a neurological condition. We also a member of the Neurology Intelligence Collaborative, co-chaired by Professor Adrian Williams who has co-signed this letter. The Neurology Intelligence Collaborative is working to coordinate and develop data and intelligence on neurological services.

I am writing regarding the review of social care data that you are conducting, and would like to offer some thoughts based on the perspective of the 12.5 million neurological cases in England.

Given the focus of our work, we are interested in social care data that shines a light on the experiences of people with neurological conditions in the system. Understanding what spending and activity is currently taking place - and what outcomes are being achieved - is an important part of identifying good practice and targeting improvements effectively.

Unfortunately, the social care data available at present provide virtually no insight into these issues as adult social services are defined by disability and need rather than condition, and the existing social care surveys do not record the conditions that an individual may have.

This issue has been recognised in recent work on Neurology. For instance, in its 2016 report on services for people with neurological conditions, The Public Accounts Committee concluded that “[t]here are no specific data on spending on social care for people with neurological conditions or on the number of people with neurological conditions receiving social care services” and called for the integration of health and social care data.

Our Patient Experience Surveys highlight the significance of social care for people with neurological conditions. Just 15% of respondents to a recent survey of 500 people with neurological conditions stated they had received an assessment from their local council for care and support needs. This seems low given 63% said their neurological condition affects their day to day activities to a moderate (30%) or great extent (33%). Overall

ratings of social care experience are lower than ratings of health care experience, with the percentage rating their care as good or excellent being 63% and 77% respectively.

We believe that there is a real opportunity to improve social care data for people with neurological conditions, which could provide crucial insights into social care that simply aren't possible at the moment. One option would be to add a question to the existing social care surveys to allow them to capture what long term condition(s) an individual has¹. By making this a generic question about long term conditions, this would also serve as vital information for other long term conditions.

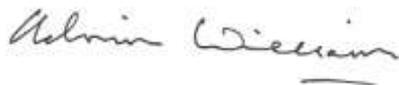
More ambitiously, linking health and social care data would also represent a radical improvement in our understanding, and would align with the increasing emphasis on integration.

We would be delighted to engage with this agenda as it moves forwards, and to continue to offer our perspective on how social care data can be improved.

Yours Sincerely



Sarah Vibert
Chief Executive, Neurological Alliance



Professor Adrian Williams,
Chair National Neuro Advisory Group, Co-Chair Neurology Intelligence Collaborative, Chair Clinical Reference Group Neurosciences.

¹ E.g one could add such a question to *The Personal Social Services Adult Social Care Survey, England*, and *Personal Social Services Survey of Adult Carers in England*. A question could be based on, for example, the question on long term conditions in the GP Patient Survey.