THE NEUROLOGICAL ALLIANCE

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Sir Andrew Dillon
Chief Executive
National Institute for Health and Care Excellence
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cc. Professor Adrian Williams, Chair National Neuro Advisory Group
cc. Patients Involved In NICE Executive Group

Dear Sir Andrew,

The guideline on Suspected Neurological Conditions has been long awaited by the neurological patient community. Our research demonstrates the time taken from first GP visit to diagnosis of a neurological condition can be highly variable across conditions and across different geographies. This is to the detriment of both patient outcomes and health service efficiency. Indeed, supporting GPs and other primary care professionals to better recognise and refer patients with suspected neurological conditions is one of our main calls to action as a campaigning group. Which is why, from the outset, The Neurological Alliance and its members have been keen to work with NICE to ensure this guideline is effective in addressing delays in detection and referral of neurological conditions, as well as inefficiencies in the pathway.

I am writing to you to raise a number of matters, but most importantly to find out the next steps for the guidance. Following the public consultation, in December 2017 The Neurological Alliance reviewed an updated draft of the short version of the guideline as part of our role on the National Neuro Advisory Group. I understand that early in 2018 a meeting took place with Joe Korner (maternity cover for my post) and Professor Williams, along with staff and committee members from NICE. This is the last communication the Neurological Alliance had about the guideline and we are increasingly under pressure from our patient organisation members about the next steps. We note that the expected publication date has been stated as TBC on the NICE website for several months now.

Clearly, we are keen this guideline is published so it can start to address some of the issues with this part of the patient pathway. However, we also want to ensure the final guideline is comprehensive in its content, easy to use for primary care professionals, and widely taken up by the health system. While some of our concerns were addressed (notably the welcome inclusion of headache in the list of symptoms), a large number were not. One of our main concerns around signposting to appropriate information and support was not addressed. Similarly, very few of our patient organisation members had their concerns addressed in the second draft of the guidance. Many echoed the concerns of the clinical neurology community that the contents were inconsistent and not pitched appropriately for a generalist audience. Overall, from what we

have seen in the latest draft of the short guidance (we have not had sight of the next draft of the long guidance), we do not believe this guideline is fit for purpose.

We appreciate the scale of the task involved in developing a guideline on suspected neurological conditions. The sheer number of conditions involved and breadth of potential presentations of symptoms means developing guidance that is both comprehensive and usable was always going to be challenging. Furthermore, there is very little evidence in relation to recognition and referral of patients with suspected neurological conditions. This meant that the usual evidence-based approach followed by NICE could not be followed in this instance. We understand that NICE chose to follow a consensus based approach instead, but as you are aware, at present there is little consensus in the wider patient and professional community about this piece of guidance.

We are keen to work with NICE to agree how to address the issues the patient and clinical community have with the draft guidance. Our overall priority is for the original intention of the guidance to be fulfilled so that it can support improvements in care for people with neurological conditions. I would welcome the opportunity to discuss this further with you, should that be helpful.

Yours sincerely

Sarah Vibert
Chief Executive

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