**Neurological patient experience survey 2016**

**Frequently asked questions document**

**1. Why are you launching a neurological patient experience survey?**

The neurological patient experience survey is a vital tool helping the Neurological Alliance gather important information about the experiences of care, treatment and support received by people affected by neurological conditions. It will also help us understand what progress has been made in improving neurological services and what still needs to happen.

The previous iteration of our survey, conducted in 2014, produced a wealth of data and information which has been used for a wide range of campaigning and research activity. This year’s survey will assess progress compared to 2014 as well as incorporating a wider range of additional questions and topics to help us gather a fuller picture of what it is like living with a neurological condition’. The survey results will be written up into a report and published early 2017, and will set out a comprehensive picture of what is happening in relation to neurological services, care and support, and make recommendations about how they can be improved. We will share the report with decision makers who have influence over how NHS and social care services are designed and delivered.

**2. When will the survey be launched, and what is the closing date for responses?**

The survey will go live on 30th June 2016, with a closing date of Monday 30th September 2016.

**3. Is the survey available in a paper format?**

The survey is set up in an online format only. This means that you will need an internet connection to complete the survey. However, you can download a printable copy from the Neurological Alliance website which can be filled in on paper and then be inputted online at a later date by a friend, family member or carer on the respondent’s behalf.

**4. How is the survey going to be promoted and who are the target audiences?**

The survey will be sent out to organisations and individuals from across the neurological community, as well as key stakeholders within the NHS and the Government. We are also asking for the Neurological Alliance’s members to publicise the survey among their own networks on their websites and via email and social media.

**5. Can I answer the survey as someone who cares for an individual with a neurological condition, or is it only open to people with a neurological condition?**

This survey is only open to individuals with a neurological condition. You can of course support the person you care for by filling in the answers on their behalf.

**6. How will you ensure my response remains confidential?**

All responses will be kept completely anonymous. Where the survey asks for postcode information, this is in order to identify the local area you live in for comparison purposes and to understand local variations. This data will be privately shared with Public Health England in order to map each response to your local area. After this is completed, all postcode information will be permanently deleted. Your postcode information will not be published or shared with anyone else.

All publicly shared information will be fully anonymised. We have provided an option in the survey for people to provide their contact details if they wish. If you chose to provide contact details, they will not be published or shared with anyone else. We will only contact you if you state in the survey that you are happy to be contacted, and we will not share this information with anyone. If you choose to be contacted and provide any further information, it will not be shared or published without your explicit consent.

**7. Who can I contact should any questions/queries come up whilst completing the survey?**

In the first instance, please contact your relevant patient and representative organisation who should be able to answer your query or direct you to the appropriate individual and/or body for further information. There are links to member organisations’ websites on the [Neurological Alliance website](http://www.neural.org.uk/directory-of-organisations).

**8. How and when will the survey’s findings be collated and promoted?**

Launched on Monday 30 June 2016, the survey will remain open until **30th September 2016**, during which time the responses will be captured online using the Survey Monkey programme. Once closed, the survey responses will be analysed. The findings will appear in the Neurological Alliance’s first annual variations report, which is due for publication at the end of 2016.