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**General Practitioners
Committee**

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Dear Dr Seccombe

Neurological Survey Questionnaire

I recently met with you and other members of the Healthcare Commission in order to give our views on the proposed Neurological Survey Questionnaire. We strongly support this effort to determine the actual standard of neurological care in the UK; however, obtaining reliable data through the survey using its proposed process and design will be almost impossible. Following discussion of the questionnaire, we identified a number of problems, and offered some suggested solutions, which are set out below:

Definition of neurological disorders

It is essential to clearly define what a 'neurological condition' is in the context of this survey.

- Neurological conditions vary enormously in their complexity, severity, diagnosis, and treatment. For example, patients with epilepsy may range from those who have not suffered a seizure for years and do not require medication or review; those who are stable on long-term medication and require only a brief annual review; and those with complex epilepsy who are cared for only by specialists and not by their GP.
- In some cases, a minor neurological condition, such as neuralgia, may be diagnosed by a GP from the symptoms displayed by the patient, but never confirmed by any third party.
- Impaired neurological functioning may be the result of a disorder which is not classified as 'neurological' – for example, strokes are usually classified as a cerebro-vascular problem and are now often managed by physicians who are not nominally neurologists.
- Patients may suffer simultaneously from multiple neurological conditions; care provided may be highly effective for one of these but less so for another. In such a case, would the survey measure the quality of care provided in management of the neurological conditions as a whole, or per condition?

Definition of survey sample

There is a need to define the target population of the survey more precisely.

- Patients may have a neurological condition for which they require no regular care or only very occasional care, for which there is no care available, or for which they have not sought treatment. Surveying patients who have contacted medical practitioners within the last year because of a neurological condition would exclude such patients.

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- The experience of care for patients with neurological conditions and assessment of the quality of that care will be vastly different between patients - for example, some patients classed as having a neurological condition require 24-hour specialised medical care; others require no more than an annual check up from their GP; many require no medical input at all. We believe the Healthcare Commission should be very clear which population it is trying to reach and then the survey questions must take into account such variations in the types of care provided to the wide range of patients with a 'neurological disorder'.

Obtaining data

It is clear that there will be great difficulties in obtaining a representative sample of patients with neurological disorders using GP databases.

- GPs usually refer patients to secondary care specialists in cases of suspected neurological disorders. The disorder may be confirmed by the specialist, and all future care provided in the secondary/tertiary sector, bypassing the GP. If a patient does not require medication for their neurological condition, then their GP record may be incomplete.
- It would not be possible for a GP to identify all patients within a practice list who had a neurological condition. Patients with epilepsy are recorded as part of the QOF and practices could in theory provide a list of these patients. However it would not be a comprehensive list of all patients with neurological conditions, nor would it record the severity of these conditions. GPs do not keep registers of rare or minor conditions, and the computer coding of many conditions are complex and variable.
- There are major confidentiality issues for practices who are asked to provide lists of patients with neurological conditions, and with researchers contacting them. Charities are very unlikely to be able to provide a representative population sample of respondents, although they may pick up people who are not included on medical lists. Carers/relatives of patients may have to provide information on care quality in cases where the patient is unable to do so his/herself e.g. in the case of minors, patients with severe communication disorders.
- We believe that the best way to reach the widest possible group of patients who have neurological conditions would be to use data held by secondary or regional neurological centres. The vast majority of patients with neurological conditions will be known to them, and are likely to be reviewed at least on an annual basis. We believe that using this route it would also be possible to avoid the major confidentiality issues that GPs and practices would have faced. If this method is adopted we believe the survey would have greater validity and might be more successful.

We would be happy to meet with your team again when they are designing the survey, particularly if survey questions are to ask about care received from GPs or their teams.

Kind regards

Laurence Buckman
Chairman, General Practitioners Committee