THE NEUROLOGICAL ALLIANCE

Clinical Reference Group Three Year Review - 2019

General points

- What does 'greater flexibility' mean in terms of the number of PPV members? We feel that a minimum number should be stated to avoid recruitment of PPV members not being prioritised.
- We have a concern about reduction in clinical members to between 3 and 7, especially given the revised neurosciences CRG will now cover neurology, neurosurgery and pain (see below). At present we have 8 clinical members – four representing neurology and four neurosurgery.
- We understand the rationale for moving away from geographic representation of clinicians, given there are now seven NHS regions. We do have concerns about this however – this was a strength of the CRGs given delivery of specialised is regional and local. The move towards STPs as a delivery vehicle perhaps makes this even more important. Furthermore, for neurosciences, each region has a very different delivery model – what will work in one area of the country, will not work elsewhere.
- We are interested in the pilot of the 'whole pathway' approach to the CRGs. We are already attempting to do this via the National Neuro Advisory Group which is chaired by the Neurosciences CRG Chair. Can neuro be a 4th pilot given we have already gone some way down the road to establishing this as a new model? Or at the very least be evaluated as part of the wider pilot as we are two years in and there are lessons to be learnt?

Pain/Neurosciences merger specific points

Adding to the complexity of neurosciences

The breadth of conditions that fall under the banner of 'neurology' is often a cause of the lack of focus on neuro by commissioners and other decision makers. Many neurological conditions are often poorly understood, sometimes even by specialist clinicians, due to their complexity. Adding pain to this disease area in terms of the way it is considered by NHS England as a commissioner will only add to this problem.

Dilution of patient voice

There are current three PPV reps on neurosciences and 2/3 on pain. If you bring the two CRGs together, does this mean the number of PPV reps will reduce overall? If so, the PPV aspect will be greatly diluted. This may mean potentially significant policy changes are agreed without appropriate PPV input.

We do not believe that working groups are sufficient to get around this problem as many of the main decisions are – rightly – made at the CRG. We also have concerns about the governance of working groups which do not usually have terms of reference or a formal process for ensuring PPV involvement.

There will be a reduction in clinical input to both pain and neurosciences:

Similarly, on the clinical side, a consolidated CRG will slim down expertise in relation to both neurosciences and pain. Neurosciences is already a very wide discipline but the current CRG covers most aspects in terms of clinic expertise – this is through having 8 rather than 4 clinical representatives to cover both neurology and neurosurgery across the four NHS regions. If the pain CRG is merged with neurosciences, we do not see how good clinical representation will be possible given the limited number of clinical spaces on the CRG. The new CRG arrangements propose a minimum of three and a maximum of seven clinical representatives. 12 clinical representatives will not be manageable, but equally seven spread evenly across pain, neurology and neurosurgery will mean greatly diluted clinical input compared to the current arrangements.

It will add to the overall workload of the Chair and other members:

Specialised pain has some cross over with neurosciences but is far wider than this. The NHS England programmes of care that specialized pain relates to include women and children, cancer, and mental health (in terms of medically unexplained symptoms). There are interdependencies between many of the CRGs but adding pain to neurosciences will mean the combined neurosciences/pain CRG will need to work collaboratively with an even wider range of other interdependent CRGs. This will add to the already stretched workload of the members, particularly the Chair.

We (The Neurological Alliance) strive to ensure we represent pan-neurologically in our PPV role for the CRG. We seek input from our member charities and beyond when specific topics are being discussed in order to ensure strong patient voice. There are multiple examples of us bringing patient voice into the discussion on disease specific issues. This role will be much harder if we expand the remit to also cover pain.

Meeting agendas and commissioner workload will become unmanageable in the time available

The addition of pain to neurosciences will dilute an already busy agenda, potentially making this unmanageable in terms of the number of policies and specifications to be developed. The neurosciences specification redevelopment has already been very delayed, in part due to the workload of the lead commissioner of the CRG. Neurosciences is currently subject to a national services review, which is on top of the CRG's 'business as usual'.