

NHS England
Skipton House
80 London Road
London
SE1 6LH

Dear Mr Stevens,

We are writing as patient groups involved with the work of Clinical Reference Groups (CRGs) within the National Programme of Care for Cancer to express our opposition to the proposed revisions to CRGs as outlined in the NHS England consultation document.

In particular, we are concerned that a number of existing site-specific CRGs would be disbanded, and merged into a broader Cancer Surgery CRG, whose focus would be more thinly spread across a range of different cancer types.

We believe that the loss of these site-specific groups would have a negative impact on NHS England's ability to develop clinical commissioning policies in a number of specialist disease areas. The output of the CRGs over the last three years has demonstrated the value of maintaining site-specific groups with specialist clinical and patient expertise.

The CNS Tumours CRG has adopted and revised a number of service specifications for Brain Cancer and Central Nervous System Tumours, Complex Neurofibromatosis Type 1 and Neurofibromatosis, utilising the specialist clinical expertise of the Group's membership.

The clinical expertise represented in the membership of the CNS Tumours CRG included oncologists, neurosurgeons and radiographers, providing a depth of knowledge about treatment areas across the care pathway for CNS Tumours. Additionally, there were a number of professional bodies involved in the Group, such as the Royal College of Radiologists.

By disbanding the site-specific CRGs, there is a risk that this clinical expertise would be diluted within a CRG that would allow only limited representation for each tumour type.

The Sarcoma CRG is leading vital work to improve services for patients with sarcoma, generating innovative ideas and opportunities across sarcoma clinical services. Sarcoma UK's recently published *National Sarcoma Survey 2015* (reporting the experiences of 650 patients with sarcoma) clearly illustrates the



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need for high quality specialised services for sarcoma and more clarity around the pathways into these services.

The new sarcoma service specification developed by the sarcoma CRG (currently out for public consultation) is an example of very effective partnership working between clinicians, patients, patient groups and other stakeholders. It has huge potential to bring about significant improvements for sarcoma patients in earlier diagnosis and prompt access to sarcoma specialised services. However, this potential will only be achieved if a dedicated focus on sarcoma is maintained within specialised commissioning, through an expert sarcoma clinical reference group.

Site-specific CRGs also provide the opportunity to patients and carers who are personally affected by a disease area to help shape commissioning policies and service specifications for cancer at a national level. We believe that the proposals to reduce the number of patient and public voice (PPV) representatives from four to two within each CRG would reduce the ability of patients to contribute to the commissioning of specialist cancer services in England.

Therefore, we call on NHS England to reconsider the proposed revisions to CRGs, and to meet with us to discuss these concerns.

Yours sincerely,



Sarah Lindsell, CEO

The Brain Tumour Charity

&



Lindsey Bennister, CEO

Sarcoma UK



Winner



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