

Sarcoma UK's Response to NHS England's Consultation on Proposed Revisions to Clinical Reference Groups (CRGs) in Specialised Commissioning

Sarcoma UK's response to the consultation questions are below:

I. Do you have any comments on the proposed revisions set out in section 2 of the engagement guide around the resourcing of CRGs, the remuneration of members or the number of members in each CRG?

Sarcoma UK welcomes NHS England's proposal to provide administrative resource to CRGs, which should bring about more efficient operation of CRGs and increased outputs. The sarcoma CRG has delivered some excellent work under challenging circumstances. The limited administrative and financial resources offered to the group necessitated a significant level of commitment and dedication from sarcoma clinicians and patient representatives, who worked together in a highly effective way to deliver the outputs of the group.

Sarcoma UK recognises that the CRG Chairs play a vital role and give significant amounts of time to the role. However, we do not believe that this role should be remunerated as proposed. If administrative support is increased, this should provide sufficient additional support to Chairs. Financial investment from NHS England should be allocated to retaining the specialist CRGs including sarcoma, where there is real potential for improving service delivery and patient outcomes.

We also have concerns about the independence of CRG Chairs who are remunerated by NHS England, particularly in the context of the new policy development process, which gives greater powers to CRG Chairs to take action in lieu of consultation with the CRG as a whole.

Sarcoma UK is concerned that the reduction in the numbers of members in each CRG (and the reduction in the numbers of CRGs) will dilute the expert specialist nature of CRGs. The original premise of CRGs was to bring together the expertise needed to commission complex specialised care at a national level. These proposals reduce the number of clinical and patient members whilst broadening the remit of the group. This is likely to result in the loss of the specialist clinical expertise. This is needed to inform the delivery of specialised services for sarcoma.

II. Do you have any comments on the proposed revisions set out in sections 3-8 of the engagement guide relating to the numbers and remit of the CRGs within each National Programme of Care?

Sarcoma UK does not support the proposed changes to the numbers and remit of the CRGs within the Cancer National Programme of Care. The proposals are clinically inappropriate for sarcoma which requires a multi-disciplinary approach to treatment and care that cannot be adequately addressed within one CRG (whether surgery,

radiotherapy or chemotherapy). The lack of recognition in these proposals of the complexity of cancers such as sarcoma is very concerning and disappointing in light of the important work already initiated by the sarcoma CRG. Clinical Reference Groups with a broad remit are unlikely to understand or prioritise the requirements of services for complex or rarer cancers such as sarcoma.

We acknowledge the reference to the development of subgroups within new CRGs to maintain service-specific expertise and engagement. We believe that these groups are key to the success of any new approach, however, much more detail is needed about the nature and use of these groups.

In addition, we have concerns about the post-consultation timelines which will not allow for meaningful engagement around the issue of subgroups or proper response to consultation feedback. Engagement by NHS England with the current CRGs around their role in the new structure is vital in order to protect their work and maintain progress.

III. Are there any other changes or revisions that NHS England should consider to the role, function and membership of CRGs?

Sarcoma UK supports the model of clinically-led commissioning for specialised services. However, we believe that services for complex cancers such as sarcoma need to be developed by a clinical reference group with sarcoma expertise (clinical and patient).

There is no evidence that the proposed model of CRGs (with a much broader remit) will improve outcomes for patients, and we believe it could impact negatively on outcomes for patients who have complex or rare cancers such as sarcoma.

The sarcoma CRG meets its purpose of driving “improvements in the quality, equity, experience, efficiency and outcomes of commissioned specialised services” for sarcoma and works well. Therefore, we question the rationale behind the new proposals which could be a big step backwards in the care of sarcoma patients.

IV. Please provide any comments that you have about the potential impact on equality and health inequalities which might arise as a result of the proposed revisions that we have described?

NHS England’s values are stated as promoting equality and addressing health inequalities, giving “regard to the need to reduce inequalities between patients in access to, and outcomes from healthcare services and to ensure services are provided in an integrated way where this might reduce health inequalities”.

These proposals do not meet these values or achieve the equity that they intend for sarcoma patients, and are likely to disadvantage people with cancers where access to specialised services is a significant problem, such as sarcoma. Sarcoma patients report some of the poorest experiences of any cancer type, significantly lower than the

experiences of people diagnosed with the most common cancers. (*National Cancer Patient Experience Survey 2014*).

3,800 people are diagnosed with sarcoma each year and a third are not referred appropriately to sarcoma specialised services. Of these, 10% will be treated inappropriately for another condition and 10% will be told by their GP that their symptoms aren't serious and not to come back if they persist (*The National Sarcoma Survey 2015: Transforming patient experience. Sarcoma UK*). It is well established that a significant number of sarcoma patients visit their GP three or more times before being referred for investigations (*Pre-referral GP consultations in patients subsequently diagnosed with rarer cancers: a study of patient-reported data. Silvia C Mendonca, Gary A Abel, Georgios Lyratzopoulos British Journal of General Practice; March 2016*). This evidence points to the need for a very specific focus and prioritisation within specialised services on access to services for sarcoma patients, to achieve equality with the more common cancers.

The expertise provided by the sarcoma CRG to shape sarcoma services is not sourced by NHS England through any other means. We believe that these proposals will halt the positive progress currently being made in improving sarcoma services, and will greatly disadvantage sarcoma patients.

The proposals also significantly disadvantage sarcoma patients in relation to their opportunities to contribute to the development of sarcoma services at a national level. The sarcoma CRG has been an excellent model for clinicians, patients and patient organisations to work collaboratively to improve services.

Sarcoma UK
2 March 2016