

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

Background

The treatment and care of sarcoma patients in England is delivered under the NHS England model of 'specialised commissioning'.

This is where services (usually for rare and complex conditions) are provided by relatively few specialist centres and overseen nationally by NHS England. Specialised services are underpinned by national policies that determine how they should be set up and delivered. The aim is for consistency of service wherever patients are treated.

Clinical Reference Groups (CRGs) were established as the primary source of clinical advice to NHS England in support of specialised commissioning. The establishment of a sarcoma CRG in 2013 was a very positive step forward for sarcoma patients and clinicians. It was an important recognition by NHS England of the inequalities that sarcoma patients face in accessing specialist services. This is now under threat.

Sarcoma Clinical Reference Group

The sarcoma CRG is chaired by Professor Jeremy Whelan (London Sarcoma Service, UCLH) and includes clinical members from sarcoma services throughout England. There is strong patient representation and Sarcoma UK is represented by our Chief Executive, Lindsey Bennister.

The sarcoma CRG is leading vital work to improve clinical services for patients with sarcoma and has made excellent progress under difficult conditions with few resources. Sarcoma UK's recently published *National Sarcoma Survey 2015* (reporting the experiences of 650 patients with sarcoma) clearly illustrates the need for high quality specialised services for sarcoma and more clarity around the pathways into these services.

A key achievement of the sarcoma CRG is the development of a new 'service specification' that sets out how sarcoma services should be set up and delivered in England. This service specification (currently out for public consultation) is an example of very effective partnership working between sarcoma clinicians, patients, patient groups and other stakeholders. It has great potential to transform sarcoma patient experience, in particular improving earlier diagnosis and bringing about faster access to sarcoma specialised services.

The proposals

NHS England proposes to reduce the overall number of individual cancer CRGs. This will result in the loss of the sarcoma CRG, and any further work in relation to sarcoma will be incorporated into a broader cancer surgery CRG. There are no plans to utilise the sarcoma expertise (clinical and patient) currently provided by the sarcoma CRG.

Sarcoma UK's position

Sarcoma UK has serious concerns about how these new proposals will impact on the future delivery of sarcoma services and ultimately on outcomes for sarcoma patients. We believe that a sarcoma CRG must be retained within the new approach, with a formal role providing clinical and patient expertise in order to drive forward improvements in services.

Sarcoma UK
2 March 2016