

# Sarcoma Cancer Services Consultation Guide

## Purpose of this document

---

NHS England is committed to working with a wide range of patients, patient groups and other stakeholders in the development of its commissioning of specialised services. A public consultation is an opportunity to check whether proposals are right and supported, the public understand their impact, and identify any alternatives before decisions are made.

NHS England has launched a consultation to seek views on proposed changes to Sarcoma Cancer Services. The consultation will run from 12<sup>th</sup> October 2018 to 11<sup>th</sup> December 2018. This document sets out:

- How care is currently provided to people with sarcoma.
- Issues with the way care is currently provided.
- The proposed changes and reasons for these.

The document also has information about how you can share your views with NHS England. At the end of the consultation period, all feedback will be considered and a decision will be made about how services should be delivered in the future. Conversations will then take place at a local level with the Sarcoma Cancer Services to determine the best way to deliver this care at a local level.

We recommend that you read this consultation guide alongside the following:

- [Service specification](#) – this document sets out the requirements and standards that Sarcoma Cancer Services must adhere.
- [Impact assessment](#) – this document aims to evaluate the potential impact of the proposed changes on both patients and services.

The service specification for Sarcoma Cancer Services being consulted on is an amalgamation of two separate existing service specifications (bone sarcoma and soft-tissue sarcoma). Therefore it is not a new service specification, but a revised one. This amalgamation recognises that services for these diseases are closely related.

## Context

---

### What is sarcoma?

- Sarcomas are rare cancers.
- There are over 100 different types of sarcoma cancers.

- There are approximately 3,800 new cases of sarcoma diagnosed each year, making up 1% of the total cancer diagnoses in the UK.
- There are two main subtypes of sarcoma – 1) soft tissue sarcoma and 2) bone sarcoma.
- Out of the 3,800 cases of sarcoma diagnosed per year, it is estimated that 3,300 people have soft tissue sarcoma and 500 people have bone sarcoma.

### Who is affected by sarcoma?

- Sarcoma can affect people of any age.
- In general, people with soft-tissue sarcoma or bone sarcoma tend to be younger than the majority of cancer patients.
- 57% of soft tissue sarcomas affect people under the age of 65, and about a quarter of all bone sarcomas occur before the age of 30.
- Sarcomas make up 15% of all childhood cancers (0-14 years) and 11% of all cancer diagnoses in teenagers and young people (15-25 years).

## How is care currently provided to people with sarcoma?

Sarcomas are rare and complex, therefore surgery for bone sarcoma and for most soft-tissue sarcomas is concentrated into specialist services across England. Currently in England, there are 15 designated soft-tissue surgery **Specialist Sarcoma Centres**, of which five are jointly designated to undertake bone and soft-tissue surgery. The table below shows the distribution of Specialist Sarcoma Centres across England (a full list can be found in the appendices of the Service Specification document):

Region	Joint bone and soft-tissue sarcoma	Soft-tissue sarcoma (only)
North	2 centres	4 centres
Midlands and East	1 centre	2 centres
London	1 centre	1 centre
South	1 centre	3 centres

These Centres are responsible for hosting the sarcoma multi-disciplinary team (MDT), which includes all specialist staff required to deliver a high standard of care in a particular service, such as surgeons with specialist training in sarcoma and specialist sarcoma oncologists. All patients with a suspected or confirmed diagnosis of sarcoma are expected to be referred to the sarcoma MDT for review and discussion, about their diagnosis, treatment and follow-up care. The MDT is expected to advise on the best treatment plan for each patient, and also the appropriate place that they should receive their care.

The Specialist Sarcoma Centres work as a network with **Local Sarcoma Units**, and these networks are referred to as **Sarcoma Advisory Groups (SAGs)**. There are currently 11 SAGS across England. The SAGs are responsible for ensuring:

- There are clear referral pathways (i.e. how people diagnosed with sarcoma are then referred for treatment).
- There are treatment protocols in place in order to manage sarcoma care across their network (i.e. to ensure patients receive the same standards of care across the network and treatment is in line with best practice).

**Local Sarcoma Units** can be based in specialist cancer hospitals (tertiary) or in district general hospitals (secondary). Local Sarcoma Units are responsible for hosting MDTs for specific cancer tumours and providing some aspects of the diagnosis, treatment and follow-up care for people with sarcoma.

People with sarcoma may be treated in the Specialist Sarcoma Centre or in Local Sarcoma Units depending on the type of sarcoma they have; where patients are treated for particular types of sarcoma will be agreed by the SAG. As sarcoma can occur in any part of the body, sometimes it will require the MDT input of another speciality (e.g. gynaecology, breast). It is therefore important that Specialist Sarcoma Centres work closely with other cancer services.

- All bone sarcoma surgery must be delivered in one of the five bone sarcoma centres (see table above).
- While most soft-tissue surgery cases should also be in a Specialist Sarcoma Centre, some forms of soft-tissue sarcoma cancer surgery (e.g. gynaecology, breast) which requires the surgical expertise of other MDTs, may be performed outside of the Specialist Sarcoma Centre (for example in a Local Sarcoma Unit).
- Chemotherapy and radiotherapy services for sarcoma patients may also be delivered outside of the Specialist Sarcoma Centre.
- Follow-up care may be delivered in the Specialist Sarcoma Centre or in Local Units (even in instances where surgery took place elsewhere).

The Sarcoma Networks (SAGs) also need to have formal working relationships with the Children Cancer Networks and Teenage and Young Adult Cancer Networks to ensure there are clear referral and treatment guidelines for children with sarcoma.

## **Why do we need to change the way we deliver these services?**

---

NHS England coordinated a review of Sarcoma Cancer Services which has identified a number of issues in the way care is currently provided. These are outlined below.

What is the issue?	What does this mean for patients?
<p>Currently there is variation in how the SAGs function across the country. This is reported through NHS England's Quality Surveillance records.</p> <p>This can lead to a lack of robust referral and treatment pathways across the SAGs, as well as a lack of oversight and governance of these pathways.</p>	<p>This may mean that some patients are not being treated by the most appropriate clinical team or receiving the appropriate clinical treatment, for their particular sarcoma. This will likely impact on patients' experience and outcomes.</p>
<p>All patients with a suspected or confirmed diagnosis of sarcoma are expected to be referred to the sarcoma MDT for review and discussion; however data from the National Cancer Registration and Analysis Service (NCRAS) shows that this is often not the case.</p> <p>Only around 40-60% of sarcoma patients are being discussed by the sarcoma MDT. However it is important to note that over 95% of sarcoma patients are recorded as being under the management of a cancer MDT (e.g. gynaecology, breast).</p>	<p>As stated above, this may mean that patients are not receiving the right level of clinical expertise in their care.</p>

## What changes are being proposed?

The new service specification has been developed by a range of stakeholders including clinicians, patient groups, commissioners and Public Health.

What is not proposed to change is the way in which Sarcoma Cancer Services are governed through the SAGs and provided by Specialist Sarcoma Centres and Local Sarcoma Units - the roles of these organisations in delivering sarcoma care is largely unchanged. The number of sarcoma services is not expected to change as a result of the proposed changes.

The main proposed changes are summarised here:

**The roles and responsibilities of the Sarcoma Networks, the Specialist Cancer Centres, and the Local Sarcoma Units have been clarified** - in particular, the role of the SAGs in determining referral and treatment pathways for different types of sarcoma (i.e.

how and where patients with particular sarcomas are cared for and treated). SAGs will make decisions about this based on the clinical expertise within their network and also the travel distances for patients. Even though this could mean changes to current patient pathways, it is expected that this will impact only on a small number of patients. For example, a patient's treatment could be moved from the Specialised Sarcoma Centre to the Local Sarcoma Unit depending on what the SAG agrees for that patient.

**It is essential that all patients with a sarcoma diagnosis are referred to the specialist sarcoma MDT at the Specialised Sarcoma Centres.** Data shows that the number of patients being discussed at the sarcoma MDT needs to increase, given that sarcomas are rare and specialist input is crucial. This will mean that some patients could receive different treatment plans and have their care in a different location.

**Importantly, the number of services delivering sarcoma care is not expected to change.** The revised service specification aims to make sure patients are treated in the place with the relevant experience for their given sarcoma.

To put these proposed changes into context - if a patient has a gynaecology sarcoma, they may be currently managed and treated by a gynaecology MDT in a Local Sarcoma Unit. This patient may or may not be reviewed or discussed by the Sarcoma MDT at the Specialised Sarcoma Centre. The proposed changes would expect all patients with a sarcoma to be discussed at the Sarcoma MDT, who will review the patient and may decide if there is a more effective treatment(s) for them. If so, this may mean receiving care and treatment at a different centre or unit that is more suited to their specific needs. This hospital centre or unit will still be in the geographical footprint of the SAG network.

## What do you think of these proposed changes?

---

NHS England would like to hear what the public think about these proposed changes to Sarcoma Cancer Services. Specifically:

- Do you support our ambitions to change the way we deliver Sarcoma Cancer Services?
- Do you think our proposed plans will improve the care people with sarcoma receive?
- Do you know of any problems or impacts that we have not thought about in our proposed plans?
- If so, what are they? And what do you think we need to do to resolve this?

The consultation is set to run from 12<sup>th</sup> October 2018 to 11<sup>th</sup> December 2018. There are a number of ways you can share your views with NHS England.

- Complete the [online survey](#).
- Email – [england.npoc-cancer@nhs.net](mailto:england.npoc-cancer@nhs.net).

- Write – Sarcoma Cancer Consultation, NHS England, Floor 2B, Skipton House, 80 London Road, London, SE1 6LH
- Invite NHS England – we are happy to attend meetings or events that you may be hosting to talk about the future of Sarcoma Cancer Services. Please email – [england.npoc-cancer@nhs.net](mailto:england.npoc-cancer@nhs.net)

Your views will help NHS England to further shape and refine the plans for Sarcoma Cancer Services, to ensure we are delivering safe and high quality care which meets the needs of people with sarcoma.