

# All sarcoma patients have access to the best possible care in the UK



**Getting patients treated by experts who have experience of treating and managing sarcomas is crucial. All patients with suspected or confirmed sarcoma must have their treatment agreed by a specialist multi-disciplinary team (MDT) at a sarcoma centre, sometimes jointly with age-appropriate teams or those that focus on a particular part of the body, to ensure they receive the most appropriate and best possible care.**

## Focus on the drug pazopanib

New treatments rarely come up for sarcoma, so for some soft tissue sarcomas, the results of the PALETTE trial were hugely promising. It considered the effect of a new drug, pazopanib, on survival after previous chemotherapy had failed. This is important, as earlier chemotherapies for these sarcomas have a maximum dose, and can cause severe side-effects. Despite pazopanib being shown to increase the time it takes for sarcoma to progress, the only nation in the UK with routine access is Wales. Specialist sarcoma doctors need access to the full range of clinically-effective treatments to ensure that sarcoma patients get the best possible care.

## Why is this important?

- National guidelines state that patients with suspected or confirmed sarcoma must be cared for and have their treatment agreed by a sarcoma specialist multi-disciplinary team (MDT), yet some sarcoma patients are still seen outside of this specialist setting and receive incorrect care.
- Three reasons why being treated at a sarcoma specialist centre over a non-specialist centre can have life-changing consequences:
  1. Not receiving a diagnosis from a specialist can lead to misdiagnosis and/or receiving the wrong treatment. Research from France shows that diagnoses from non-specialist centres which were later reviewed by expert sarcoma pathologists resulted in a major change in diagnosis in 20-30% of cases.
  2. Being treated by a non-specialised team increases risk of local recurrence. Specialist sarcoma surgeons are trained not to leave the patient with sarcoma cells in the edge of the tissue, reducing the chance of recurrence.
  3. Decisions made about treatment and care by a sarcoma specialist MDT at a specialist centre brings together the experience and knowledge of sarcoma experts to ensure all patients have the most appropriate treatments for their condition. Not having that knowledge could mean that patients who are not referred to a sarcoma specialist centre may not receive the same access to possible future treatments through clinical trials.
- New medicines for sarcoma are scarce, with many medicines currently used having been around for many years. However, even when new medicines do have successful clinical trial results; clinicians are still not able to access them.
- Technology appraisals for new medicines are not adequately set up to consider drugs for less common cancers like sarcoma. Due to the rarity of sarcoma, getting a large enough sample of patients to take part in a trial is problematic. Appraisals systems are not flexible enough to allow for uncertainty, so even when drugs are shown to work, they are not accepted for routine use on the NHS.
- Pharmaceutical companies do not feel incentivised to conduct research into new sarcoma drugs, under fear that even if the drug is successful, they will not recoup the money spent on its development.

**+**  
**1 in 7**

The infographic consists of a blue bar with a white plus sign at the top. Below the plus sign, the text "1 in 7" is written in large white font. Below this, a smaller white text block contains the full explanation of the statistic.

**1 in 7 (14%) sarcoma patients are not treated through a specialist sarcoma multi-disciplinary team (MDT) at a specialist centre.**

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## Our priorities

1. Actively influence primary care professionals to improve knowledge of sarcoma referral pathways and push for suspected sarcoma to always be referred to a sarcoma specialist centre.
  2. Work with location specific cancer and children's or young adult's teams to ensure sarcoma specialist teams involvement.
  3. Campaign to ensure that patients/doctors have access to the full range of clinically-effective treatments to treat sarcoma.
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**“Patients whose care is coordinated by a sarcoma specialist centre by a sarcoma MDT not only get more accurate diagnoses, but receive better care. We want to ensure that every sarcoma patient is recognised and diagnosed as quickly and accurately as possible, and that specialist sarcoma teams have access to the full range of clinically-effective treatments.”**

**Bradley Price, Sarcoma UK's Policy and Public Affairs Manager**