

Written evidence submitted by Sarcoma UK (ECS0020)

About Sarcoma UK

Sarcoma UK is a national charity that funds vital research, offers support for anyone affected by sarcoma cancer and campaigns for better treatments. It is the only cancer charity in the UK focusing on all types of sarcoma. It works to ensure everyone affected by sarcoma receives the best treatment, care, information and support available and to create the treatments of the future.

About sarcoma

Sarcomas are uncommon cancers that can affect any part of the body, on the inside or outside, including the muscle, bone, tendons, blood vessels and fatty tissues. Sarcomas commonly affect the arms, legs and trunk. They also appear in the stomach and intestines as well as behind the abdomen (retroperitoneal sarcomas) and the female reproductive system (gynaecological sarcomas). There are around 100 different sub-types of sarcoma, which can be largely split into three groups: soft tissue sarcomas, bone sarcomas, and gastro-intestinal stromal tumours (GISTs).

The Cancer Workforce Plan committed to the expansion of capacity and skills by 2021

There is a clear and fixed deadline for implementation for this commitment. Given the added pressures of pandemic on staff, this may have had a negative effect on the capacity and skills of the cancer workforce. Within sarcoma specifically, there were no funding commitments made to support these commitments.

Sarcoma centres are under-resourced in terms of workforce. The NHS Service Specification for Sarcoma,¹ published in 2019, makes formal arrangements that all patients should have their care co-ordinated by one of the 15 sarcoma specialist centres in England. Centres serve most patients as a diagnostic and treatment service, or treatment can be carried out locally where appropriate. Specialist centres also manage long-term follow-up, and specialist palliative care and survivorship.

In a majority of cases, confirmation of diagnosis (particularly related to sub-type) is performed by specialist centres. Patients are referred to these centres with some or no work-up (scans and other diagnostic tests) for diagnosis. However, due to issues arising in the cancer workforce, sarcoma specialist centres see too much of their capacity being taken up with benign cancers. Whilst it is essential to rule out certain suspicious tumours of being cancerous, conversations between Sarcoma UK and specialist clinicians make it clear that a significant number of patients with benign lumps

¹ NHS England, 2019, Service Specification for Sarcoma - <https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2019/07/Sarcoma-Service-Specification.pdf>

need not have been referred.

This is caused by issues with radiology earlier in the pathway, whereby radiologists and sonographers have either performed a test incorrectly, or misread the results and advised on an incorrect course of action. Due to this large number of patients who are very unlikely to have cancer, coupled with the fact that all patients referred are discussed at a sarcoma multi-disciplinary team (MDT), there are significant pressures on the staff in sarcoma specialist centres. This could be improved by a specific focus on sarcoma professional education and recruitment, or by other areas outlined in the diagnosis stages of this submission.

Furthermore, for those who are diagnosed with a sarcoma, access to a specialist pathologist is essential. Accurate diagnosis of sarcomas is difficult, with the many subtypes sometimes being indistinguishable to the naked eye under a microscope. Access to gene fusion testing and a specialist histopathologist is critical in sarcoma diagnosis. This is demonstrated by a French study which showed that over 40% of primary diagnoses were changes when sarcoma diagnostics were interpreted by a sarcoma specialist pathologist.² However, in the UK there is a shortage of histopathologists who are knowledgeable in sarcoma, with the largest centre struggling to recruit this position.

Ultimately, workforce improvements to help rare cancers can be performed through both secondary and tertiary care. However, the methods employed seem to be a blunt tool focusing on the quantity of staff and expansion of new skills, rather than looking to improve the quality of work of existing staff or recruiting particular skills within specialist centres. As such, there has been little improvement for sarcoma.

A faster diagnosis standard from 2020 to ensure most patients receive a definitive diagnosis or ruling out of cancer within 28 days of referral from GP or from screening

The COVID-19 pandemic meant a delay in the rolling out of the Faster Diagnosis Standards to start from April 2021.

The Faster Diagnosis Standard is reliant on patients with symptoms of cancer being referred on an urgent cancer referral pathway. This will undoubtedly have an impact on certain cancer with specific symptoms which are regularly recognised by a medical professional. However, this is not the case for sarcomas, where approximately 80% are not diagnosed following a 2-Week-Wait cancer referral.³

² Ray-Coquard I, Montesco MC, Coindre JM, et al. Sarcoma: concordance between initial diagnosis and centralized expert review in a population-based study within three European regions. *Annals of Oncology* 2012;23:2442-49.

³ CancerData. 2019. - <https://www.cancerdata.nhs.uk/getdataout/sarcoma>

Furthermore, there are no plans to improve this area. This has a significant impact on the effectiveness of the next commitment, as outlined below.

By 2028 the proportion of cancers diagnosed at stages 1 and 2 will rise from around 50% now to 75% of cancer patients

This commitment has a clear deadline for implementation. COVID-19 is a serious mitigating factor as to why this target may not be met. The pandemic has caused a multitude of problems in both public health and primary care which have meant that cancer patients are being diagnosed later, as demonstrated by the serious gap of around 35,000 cancer patients who would have been expected to have started treatment since the pandemic began.

Much has been planned by the NHS England cancer team to achieve this target, including rapid diagnostic pathways, lumps and bumps clinics, and the Galleri trial.

The main issue affecting this commitment in relation to sarcoma patients is the quantity of available data. There currently exists no statistically relevant data on the stage at which sarcomas are diagnosed in England. In 2018, only 28% of sarcomas were coded⁴ with a stage, and there is limited evidence to show that this percentage has improved since then. Having a little over a quarter of cases staged gives no real indication of the stage at which sarcoma is diagnosed, and even if the commitment target is met, it will not be demonstrative of any impact on sarcoma diagnoses.

The target is also an incredibly blunt tool, as it does not target individual cancers, but instead looks to set a target of over 75% of all stageable cancer patients to be diagnosed at an early stage. Therefore, despite sarcomas being included in the target, data will only be captured on the small proportion of sarcomas which are staged. Indeed, many of the changes have been at a national level, without delving into the complexities of individual rare and less common cancers.

However, research from Sarcoma UK has shown that the greatest issues affecting the stage at which sarcomas are diagnosed are related to awareness and education.

Firstly, delays exist because of a lack of awareness in the general public. Some attempts have been made to educate the public, but these have in the most part been a reaction to the lower number of referrals caused by the pandemic. Equally, the Be Clear on Cancer campaigns have focused on specific cancer locations or types, with little-to-no input from relevant charities, particularly in the

⁴ Public Health England data, presented at the British Sarcoma Group Conference 2020.

earlier stages of the campaigns. There has been no public education on the signs and symptoms of sarcomas, and when scoping the abdominal cancers campaign, sarcomas were not included until brought up by Cancer52, at which point it was already too late to influence the campaign. We propose that cancer awareness campaigns are run more regularly and across a more diverse set of cancers, with charities brought on as partners by NHS England. This has already been trialled in the recent prostate cancer campaign.

Secondly, issues around primary care professionals and physiotherapists recognising the signs and symptoms of sarcomas contribute to delays in sarcoma patients being referred. As previously, mentioned, fewer than 20% of sarcomas in England are diagnosed following an urgent cancer referral. Sarcoma UK accepts that some sarcomas, such as those which are not externally visible, maybe not present with red flag symptoms. However, those sarcomas which typically fall into this category (intra-abdominal, pelvic, gynaecological, and urological sarcomas) make up less than half of sarcomas.⁵ We believe that delayed diagnosis is largely due to a lack of primary care knowledge on the signs and symptoms of sarcoma. Indeed, the National Sarcoma Survey 2020 found that at their first appointment, 39% of sarcoma patients were either started on treatment for something else or were told their symptoms weren't serious.⁶ Further to this, 35% of patients had to see a healthcare professional more than 3 times before they were referred for further tests.⁷ This, coupled with a very low percentage of patients being diagnosed through urgent referrals, means sarcoma patients are unlikely to be diagnosed at stage 1 and 2, even if this is the cancer's stage when first presented to a primary care professional.

There is much which can be done to improve sarcoma diagnosis without the type of resourcing used in the existing cancer plans. As sarcoma data is poor and access to referral information lags behind by several years, it is not yet possible to say whether sarcoma diagnosis has been improved.

Sarcoma UK does believe that the 75% commitment would be appropriate should the data collected adequately for all stageable cancers, such as sarcomas. However, as it is not, a better solution may be to have individual targets for cancers which are diagnosed late, as well as targets to improve data collection in cancers with lower rates of staging.

⁵ Public Health England data presented by Dr Sandra Strauss, British Sarcoma Group Conference 2021

⁶ Sarcoma UK, National Sarcoma Survey 2020 - <https://sarcoma.org.uk/impact-sarcoma-national-sarcoma-survey-2020-full-technical-report>

⁷ Ibid.