Consultation Report

Topic details

Title of Service Specification:	Sarcoma
Programme of Care:	Cancer
Clinical Reference Group:	Specialised Cancer Surgery
URN:	1642

1. Summary

This report summarises the outcome of a public consultation that was undertaken to test the service specification proposal.

2. Background

Sarcomas are rare cancers that can affect people of any age. There are two main types of sarcoma – soft tissue sarcomas and bone sarcoma. It is estimated that there are approximately 3,300 cases of soft tissue sarcoma and 500 cases of bone sarcoma diagnosed in the UK each year.

Care for people with sarcoma is delivered by fifteen designated Specialist Sarcoma Centres, of which ten provide soft tissue sarcoma services and five provide services for both soft tissue and bone sarcoma. These centres are responsible for hosting specialist sarcoma multi-disciplinary teams (MDTs) and ensuring people with sarcoma receive the most appropriate, specialist care by the relevant experts.

Specialist Sarcoma Centres work in partnership with other hospitals which host Local Sarcoma Units through a network governed by a Sarcoma Advisory Group (SAG). Local Sarcoma Units are responsible to diagnosing sarcoma cancer and may also provide some treatment for sarcoma including chemotherapy, radiotherapy and surgery for particular types of soft tissue sarcoma.

The role of the SAG is to ensure that all providers within the network work collaboratively to ensure referral to the specialist sarcoma MDT at the Specialist Sarcoma Centre and that treatment is delivered in line with network guidelines. There are currently 11 SAGs in place across England with some networks having more than one sarcoma centre.

This is revised a service specification for sarcoma amalgamating the current existing service specifications for soft tissue sarcoma and bone sarcoma. The revised service specification has undergone stakeholder testing in line with NHS England's standard Methods.

3. Publication of consultation

The service specification was published and sign-posted on NHS England's website and was open to consultation feedback for a period of 60 days between 12th October 2018 and 11th December 2018. Consultation comments have then been shared with the Service

Specification Working Group (SSWG) and the Specialised Cancer Surgery Clinical Reference Group (CRG) to enable full consideration of feedback and to support a decision on whether any changes to the service specification might be recommended.

Respondents were asked the following consultation questions:

- 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 yes, what are these? And what do you think we need to do to resolve this?

4. Results of consultation

There were 501 responses received to the online questionnaire. In addition, four responses were received via email, giving a total of 505 responses to public consultation.

Of the 505 responses received either online or via email:

- 91% of responses received (462) were from either patients, relatives or carers of people with sarcoma. The remaining responses were received from service providers, charity organisations (Sarcoma UK and GIST Support UK), and individual clinicians.
- 99% of respondents (500) supported the proposals. Of the remaining five respondents, only two respondents stated that they did not support the proposals (less than 1% of the total responses received). These two respondents specifically raised concerns with (i) the impact of travel to specialist centres on patients and the associated financial burden; and (ii) the late diagnosis of sarcoma with diagnosis in some cases taking up to 18 months.
- 94.6% of respondents (474) believed the proposals would improve care for people with sarcoma.

A webinar was also held with senior clinicians and service providers who provide specialist sarcoma services and are part of SAGs; this webinar was attended by 10 attendees representing 7 of the 11 SAGs. Feedback from a voting held during this webinar indicated that 9 out of the 10 attendees supported the proposals and 80% (8 out of 10) felt the impact of the proposals have been appropriately understood.

The key themes from the consultation were as follows:

- The proposals did not address the issues with late diagnosis of sarcoma cancer and issues with training in primary care to identify potential patients with sarcoma.
- Patients, relatives and carers raised issues with the current provision of care relating to communication between local units and specialist centres.
- The proposals did not address the follow-up and supportive care needs of people with sarcoma including rehabilitation services, post-operative support and physiotherapy.
- Further clarification was required regarding pathology services including defining the pathology services that needed to be available 24-7.
- Radiology service provision had been omitted from the draft service specification.

- The proposals did not reference molecular pathology, the potential impact of whole genome sequencing, new arrangements for genomic testing of sarcoma and the inter-links to the genomic testing laboratories.
- Minimum caseload numbers were included in the service specification for two sub-types of sarcoma but not for others. Respondents queried why this was the case and the evidence base used to derive these recommended numbers.
- Further consideration needed to be given to the designation of centres to perform surgery for certain sub-types of sarcoma. Respondents noted that the current proposals recommend that no more than one centre in the Network is designated to perform surgery for particular sarcomas (such as head and neck sarcoma, thoracic surgery), however, in some geographies this could result in patients having to travel long distances. The need for specialist care needed to be balanced with travel and access.
- Respondents queried the impact of these proposals on the delivery of children's cancer care, commenting that children with sarcoma were better treated by Children's Cancer Principal Treatment Centres (PTCs) rather than in specialist sarcoma centres.
- The impact of travel to the specialist centre on patients and their families needed to be considered.
- Patients, service providers and clinicians queried how the proposals would be implemented and monitored.

5. How have consultation responses been considered?

Responses have been carefully considered and noted in line with the following categories:

- Level 1: Incorporated into draft document immediately to improve accuracy or clarity.
- Level 2: Issue has already been considered by the CRG in its development and therefore draft document requires no further change
- Level 3: Could result in a more substantial change, requiring further consideration by the CRG in its work programme and as part of the next iteration of the document
- Level 4: Falls outside of the scope of the specification and NHS England's direct commissioning responsibility

6. Has anything been changed in the service specification as a result of the consultation?

The following feedback was graded as Level 1 and as a result, amendments have been to the service specification:

- Pathology service requirements have been clarified and any errors in the relevant standards have been amended.
- Genomic medicine is now referenced in the revised service specification. There is now a requirement for the MDT to consider whole genome sequencing as part of the MDT decision making process and representatives from the genomic hubs are expected to be part of the membership of the SAG.
- The designation of centres to perform surgery for certain sub-types of sarcoma has been altered to enable some networks and SAGs to designate more than one centre.

This will look to minimise travel times for patients where possible, taking into account the local geography of the area.

- Access arrangements for follow-up care and wider support services have been clarified in the revised service specification. The role of SAGs in defining these pathways at a local level has now also been specified. In addition, a new section on patient information has been added to the service specification, specifically referencing requirements for holistic needs assessments, verbal and written information for patients, and appropriate referral to support services during and after treatment.
- The requirement for specialist sarcoma MDTs to ensure there are clear and documented referral and communication processes in place between providers has been re-emphasised in the revised service specification. It is important to note that strengthening the relationships between local units and specialist sarcoma MDTs is a key driver for revising the service specification. It is anticipated that through clarifying the role of the SAG these issues can be addressed. The revised service specification articulates the role of Cancer Alliances in supporting SAGs and network arrangements.

No other changes have been made to the service specification as a result of public consultation responses. All other feedback was graded as either Level 2 or Level 4 responses, and the Working Group's feedback is as follows:

- Diagnosis of sarcoma - graded as Level 4.
  Issues with diagnosis of sarcoma, particularly in primary care, are noted. This is partly due to the rarity of sarcoma, which means that primary care physicians will only rarely see cases. Furthermore, sarcoma is complex and difficult to detect. Referral from primary care and diagnostic pathways outside of the specialist sarcoma centre are outside of the scope of this service specification. However, as part of their role, SAGs and specialist sarcoma MDTs will be expected to build relationships with primary care and other cancer providers in their Network to develop greater awareness of sarcoma and improve early diagnosis.

- Omission of radiology from the revised service specification – graded as Level 2.
  Radiology service provision, supported by radiologists with a specific interest in sarcoma, are part of the core MDT membership as per Improving Outcomes Guidance and Peer Review. These documents are referenced in the service specification and compliance against these measures is included as part of structure and process measures.

- Implementation of the service specification – graded as Level 2.
  NHS England's implementation plan for the revised service specification is described within the Commissioning Plan. This sets out that local specialised commissioning teams will work with specialist sarcoma centres and Cancer Alliances to assess centre compliance against the revised service specification and ensure SAGs are fully established. Compliance against the revised service specification will be monitored by local commissioners and the National Cancer Programme of Care. A specialised services quality dashboard will be developed to assess and monitor

performance of specialist sarcoma services going forward.

- Recommended caseloads for sub-types of sarcoma – graded as Level 2.
  The service specification contains recommended caseload numbers for retro-peritoneal sarcoma and GISTs. It is important to note that the minimum caseload numbers included in the service specification for retro-peritoneal sarcoma relate to surgical case load and development of this threshold was recommended as part of Improving Outcomes Guidance (National Institute for Health and Care Excellence). These are recommended caseload numbers only and are intended to support SAGs in being able to designate Local Units to manage certain sub-types of sarcoma. The numbers were derived from clinical consensus from the Working Group.

- Impact of travel on patients and their families – graded as Level 2.
  The service specification does not alter the current number of specialist sarcoma centres. Although the service specification mandates that all patients with a diagnosis of sarcoma must be discussed at the specialist MDT this does not mean that all patients will have to travel to the centre for their treatment. Some elements of sarcoma care, including surgery for certain types of soft tissue sarcoma, can be carried out outside of the specialist sarcoma centre. However, this does need to be balanced with ensuring access to relevant clinical expertise to secure the best outcomes for patients. SAGs will be expected to work with Cancer Alliances, Specialised Commissioning and Clinical Commissioning Groups to agree the configuration of Local Units and define their exact scope of practice.

- Relationships between specialist sarcoma centres and Children’s Cancer PTCs – graded as Level 2.
  The service specification enables SAGs to agree jointly with their local children’s cancer networks and PTCs the clinical care pathways for children and teenagers and young adults (TYA) with sarcoma. This does not necessarily mean that all children and TYAs with sarcoma must be referred to the specialist sarcoma centre or MDT but joint working will be required between Networks to ensure care is delivered as effectively as possible. The standards included in the service specification were agreed by the Working Group and the Children and Young People’s Cancer CRG.

7. Are there any remaining concerns outstanding following the consultation that have not been resolved in the final service specification proposal?

None identified.