

Service Development for Soft Tissue Sarcoma Services for Adults Stage 1 OSC Briefing: For Information & Comment

PCT Sponsoring Sharon Matson, Director of Commissioning, Torbay Care Trust
Director/s: Emma Perryman, Commissioning Lead, Torbay Care Trust
Specialised Louise Tranmer, Director of Specialised Commissioning Group
Commissioning Team: Barbara Gregory, Director of Finance & Performance
Rod Walsh, Senior Commissioner for Soft Tissue Sarcoma

1 Purpose of the Report

- 1.1 To report to the Torbay Overview and Scrutiny Committee on progress towards the designation of soft tissue sarcoma services within the South West. Specifically this briefing reports on Stage 1 of the process, setting out the proposed model of care and service for soft tissue sarcoma for the areas covered by the Peninsula Cancer Network. The briefing also outlines Stage 2 of the designation (the process for selecting the provider who will serve as the designated specialised centre for the Cancer Network).
- 1.2 The service improvement proposal presented here is a model of care and service that will:
- Ensure the quality of clinical services
 - Increase early detection and safeguard accurate diagnosis of sarcoma
 - Ensure patients receive the highest quality sarcoma treatment delivered through multidisciplinary team working
 - Improve clinical outcomes and survival rates over time
 - Improve the patient experience through a stronger care pathway
- 1.3 This South West soft tissue sarcoma proposal has been received and endorsed by the two Cancer Networks whose populations will benefit from these service improvements, and also by the National Cancer Action Team.

2 Decisions/Actions Requested

- 2.1 The Torbay Overview and Scrutiny Committee is asked to:
- Note the proposed approach to providing soft tissue sarcoma services for their residents;
 - Note the improved quality and safety of service that their residents will receive;
 - Note the involvement of patients, clinicians and the public in the process to date;
 - Support the proposed approach, including the intention to designate two soft tissue sarcoma centres in the South West region, ready for service delivery in Spring 2010.

3 Current Service – what happens now?

3.1 Sarcomas are a rare and diverse group of cancers. Soft tissue sarcomas account for about 1% of all malignant tumours, and can occur anywhere in the soft tissue in the body. Signs and symptoms vary greatly depending on the site of the tumour, as do treatment options and prognoses. Soft tissue sarcomas increase in frequency with age.

3.2 The South West Specialised Commissioning Group is seeking to commission an adult soft tissue sarcoma service on behalf of the following Primary Care Trusts:

Table 1: Incidence based on adult* population

(mid-2007 population estimates from

http://www.statistics.gov.uk/downloads/theme_population/Mid_2007_UK_England_&_Wales_Scotland_and_Northern_Ireland%2021_08_08.zip)

Area	PCTs	Cancer Network	Adult Population	Actual incidence over 3 years
West of England	South Gloucestershire PCT Bristol Teaching PCT North Somerset PCT Bath and North Somerset PCT Somerset PCT Wiltshire PCT	Avon, Somerset & Wiltshire	1,388,117	309
Peninsula	Cornwall and Isles of Scilly PCT Plymouth Teaching PCT Torbay Care Trust Devon PCT	Peninsula	1,175,006	279
Dorset	Dorset PCT Bournemouth and Poole PCT	Dorset	515,324	142
Swindon	Swindon PCT	Thames Valley	130,259	Unavailable
Gloucestershire	Gloucestershire PCT	3 Counties	405,742	88
Total for South West region			3,614,448	
Total for South West Specialised Commissioning Group adult soft tissue sarcoma service planning (excluding Gloucestershire, Swindon, Dorset, and Bournemouth and Poole – see 3.4)			2,563,123	588

*This service is for adults only. Therefore children and young adults (24 years and under) are not included in any of the above figures.

3.3 Currently, patients from the Peninsula Cancer Network area (Cornwall and the Isles of Scilly, Plymouth, Torbay and Devon) are usually treated by Royal Devon & Exeter NHS Foundation Trust or Plymouth Hospitals NHS Trust. Patients from the Avon, Somerset & Wiltshire Cancer

Network area (South Gloucestershire, Bristol, North Somerset, Bath and North East Somerset, Somerset and Wiltshire) receive treatment from a combined service at North Bristol NHS Trust and University Hospitals Bristol NHS Foundation Trust.

- 3.4 People who live in Gloucestershire receive their specialised care and treatment via the Three Counties Cancer Network, commissioned by the West Midlands Specialised Commissioning Group from West Midlands providers. People living within Dorset and Bournemouth and Poole receive their care and treatment via the Dorset Cancer Network, commissioned by the South Central and London Specialised Commissioning Groups. People who live in Swindon receive their specialised care and treatment via the Thames Valley Cancer Network, commissioned by the South Central Specialised Commissioning Group. Patients from these areas will not be affected by this service improvement proposal, as their care is routinely delivered outside the South West region. The South West Specialised Commissioning Group is working closely with all of the above Specialised Commissioning Groups to ensure excellent service provision for these patients outside of the South West, although they will be able to access service within the South West if they choose to.
- 3.5 Currently, the soft tissue sarcoma service in the two Networks hosted within the South West (Avon, Somerset & Wiltshire and the Peninsula Cancer Networks) is provided by a number of NHS Trusts. Diagnostic services as well as chemotherapy and radiotherapy are provided by several Trusts, while surgery is provided mainly in three places (North Bristol NHS Trust, Plymouth Hospitals NHS Trust, and Royal Devon and Exeter NHS Foundation Trust).
- 3.6 It is difficult for General Practitioners (GPs) to make a diagnosis and referral of soft tissue sarcoma, as the disease presents in a number of different ways and is often initially thought to be another of a number of more common conditions. Soft tissue sarcoma is rare and most GPs will not suspect it from an initial clinical examination – they may only see one or two patients with soft tissue sarcomas in their entire working life. The consequence of this is that many sarcomas are discovered at hospital biopsy or during investigative general surgery, when effective surgery for sarcoma involves a more specific approach. The patient is only then referred on to a specialist centre for the specific surgery needed.
- By developing a properly structured network across the South West that can provide training and support to GPs, pathologists and general surgical hospital doctors, the commissioning team would expect earlier diagnosis of soft tissue sarcoma from specialist sarcoma biopsy and surgery in the appropriate service, and therefore better clinical outcomes for patients.
- 3.7 Currently, there is some informal communication and sharing of clinical ideas across the South West and with clinical teams in other areas, but there is no formal agreement for working together. There are also no formally established centres of excellence in the South West for clinicians to refer to for guidance and best practice in the diagnosis and treatment of soft tissue sarcoma. This means that the levels of experience and expertise can vary between hospitals providing care and treatment.

4 Proposed Service Development – how the service will be changed

- 4.1 In March 2006 the National Institute for Health and Clinical Excellence (NICE) published guidance on *Improving Outcomes for People with Sarcoma* - otherwise known as the *Improving Outcomes Guidance for Sarcoma*. This guidance sets standards to improve care for adults with soft tissue sarcomas, and the proposed change to soft tissue sarcoma services in the South West that is outlined in this proposal meets these standards.
- 4.2 The *Improving Outcomes Guidance* starts at the point of referral with a suspected sarcoma, progresses through diagnosis (including CT, MRI, PET/CT scanning, and histopathology), treatment (surgery and therapy) and follow-up care. This includes additional supporting services that provide psychological and emotional support, orthotics and prosthetics, physiotherapy and rehabilitation, and specialised palliative care as necessary. All of these components of the care pathway are detailed thoroughly in the service specification, and will be vital to the successful delivery of the service. In addition, the service specification details the possibility for shared care for diagnostic and therapeutic services (such as chemotherapy and radiotherapy) working with the guidance of the sarcoma centre's multidisciplinary team.
- 4.3 For a soft tissue sarcoma service that is clinically safe and offers surgery of the highest quality, the *Improving Outcomes Guidance* states that a soft tissue sarcoma centre must see a minimum of 100 new cases per year. Given the rarity of soft tissue sarcomas this will require a population of 2-3 million people. A 'commissioning population' of 2.6 million (see *Table 1, page 2*) would suggest the South West should have one large centre. However, the South West Specialised Commissioning Group supports the commissioning of **two centres** - located in the north and south of the region, to serve the Avon, Somerset & Wiltshire and Peninsula populations respectively, due to:
- The geography of the South West leading to extended travelling times, and the desire to make access as easy and convenient as possible;
 - The high likelihood that soft tissue sarcomas, arising in soft tissue sites all over the body, are being defined as other illnesses and are therefore not being included in the figures in Table 1. Also as soft tissue sarcomas are sometimes not initially recognised, some increase in the total number of cases will result from the proposed changes.
- 4.4 Based on discussions with a range of local and national lay and professional stakeholders, the service model for the South West soft tissue sarcoma should include:
- A South West clinical network to provide a forum for staff to work together, provide peer support, and reach agreement regarding policy and protocol, treatment pathways, new innovations and research, and service development.
 - A dedicated multidisciplinary team (supported by a weekly meeting) for soft tissue sarcoma at each specialised centre, including specialised pathology and radiology, surgery, nursing care, and other specialty services such as physiotherapy and palliative care.

- Adequate outpatient, diagnostic, surgical/theatre, and ongoing treatment capacity to support early diagnosis and ongoing treatment of soft tissue sarcoma.
 - Excellent links with other related services (e.g. palliative care, physiotherapy, orthotics and prosthetics).
 - Triple assessment (including clinical assessment, imaging, and biopsy where appropriate) at a diagnostic clinic of suspected soft tissue sarcoma.
 - A key worker for each patient to act as a point of contact and to coordinate the patient's care pathway.
 - Care close to home wherever possible and appropriate (e.g. for chemotherapy and radiotherapy).
 - Training for General Practitioners and other primary and secondary care colleagues to help improve the recognition and detection of sarcomas.
 - A model for patient transition between paediatric and adult services, with the flexibility to be tailored to each patient's individual needs.
 - All designated providers (whether the lead centres or otherwise) will be required to work together.
- 4.5 In line with the *Improving Outcomes Guidance*, a shared-care model will be encouraged for follow-up care and routine common treatment regimens (for example, chemotherapy).
- 4.6 The preferred model was chosen because it will establish a formal care and treatment pathway, managed by a multi-disciplinary team able to ensure that patients receive the best possible treatment from a dedicated, multidisciplinary, expert soft tissue sarcoma team.
- 4.7 Potential providers will be assessed against *Improving Outcomes Guidance* criteria, as well as factors that patients, carers and the public have identified as particularly important to them. The South West Specialised Commissioning Group will designate providers that have demonstrated they are best able to meet these criteria.
- 4.8 Designated centres will be expected to develop their service to allow them to provide the full service as described in the *Improving Outcomes Guidance* by December 2010. Support and supervision for centres will be undertaken by the Specialised Commissioning Group, and providers will be supported by the South West Cancer Networks and the Specialised Commissioning Group to identify areas where improvement and investment is required.
- 4.9 Should there be any change to existing patient pathways as a result of this service development, a plan for the transition of those patients currently receiving soft tissue sarcoma care with affected hospitals will be put into place. This will be outlined in the Stage 2 Briefing, once the recommended outcome of the procurement process is known.

- 4.10 Annual reviews of the number of patients in need of this service will also ensure that the rate of expansion and development is compatible with public health, education and research for soft tissue sarcoma, so that supply is closely matched to needs.

5 Expected Benefits from Proposed Service Development

- 5.1 The South West Specialised Commissioning Group is proposing to select a service provider in each of the Avon, Somerset & Wiltshire Cancer Network area (South Gloucestershire, Bristol, North Somerset, Bath and North East Somerset, Wiltshire and Somerset) and Peninsula Cancer Network area (Devon, Torbay, Plymouth, Cornwall and the Isles of Scilly). These providers will be best placed to meet NICE Improving Outcomes Guidance and the factors that local people have said are important to them. This will:
- Maintain the best possible clinical quality for patients undergoing treatment in the South West.
 - Ensure that patients treated in the South West receive the best possible quality of service, at least equal to that provided in other areas.
 - Ensure patients are confident of receiving high quality care within the South West, rather than travelling to other areas.
 - Fully support the future development of soft tissue sarcoma services by enabling specialists to share their expertise.
 - Encourage and support research, development, and the use of new techniques and treatments.
 - Develop a soft tissue sarcoma training programme for surgeons, nurses, pathologists and radiologists at specialised expert centres.
 - Coordinate participation in research on a regional and national level.
 - Develop training for GPs and other healthcare professionals in the early recognition and appropriate management/referral of suspected soft tissue sarcomas.
 - Develop robust patient pathways and processes relating to referral between hospital teams and referral for diagnostic tests.
 - Develop common protocols for follow-up and diagnostic surveillance to monitor patients with a history of soft tissue sarcoma and quickly diagnose and treat any recurrence.
- 5.2 Chosen centres will work together to ensure they meet National Institute for Health and Clinical Excellence (NICE) quality assurance criteria and the things that local people have said are important to them. Therefore, agreement of this proposal will also provide assurance that the service model meets agreed quality standards which will contribute to improved health outcomes for individuals.

6 **Engagement process**

6.1 Five stakeholder events have been held in a number of locations around the region:

- Five for patients and the public:
 - 16th December 2008 (Taunton)
 - 7th January 2009 (Exeter)
 - 15th January 2009 (Swindon)
 - 9th March 2009 (Bodmin)
 - 10th March 2009 (Bristol)
- One for clinicians and professional stakeholders
 - 27th March 2009 (Taunton)

6.2 The aim of these events was to identify a preferred service model, including aspects such as travelling distance, care closer to home, vital service components, and additional quality criterion. Hence, staff, patients and carers were asked about service standards, expected demand, the care pathway for patients (across regions where necessary), and the support that would be given to them and their carers.

6.3 In addition, a questionnaire to capture people's views on what a good soft tissue sarcoma service for the region should include was handed out to those that attended the events. The questionnaire was also available on the South West SCG website www.swscg.nhs.uk (for people who could not attend any of the events). This questionnaire was also distributed to patients by various soft tissue service providers in the region.

6.4 A full description of who and how many attended events and completed the questionnaire along with an analysis of what people said is available at <http://www.swscg.nhs.uk/consultation/>. However, a brief summary is provided below.

6.5 In total, 59 people attended the events and 80 people completed the questionnaire. Overwhelmingly, the most important factors in people's treatment were the level of expertise of the staff, and knowing that their place of treatment had the best clinical outcomes. People also found it important to receive care from the same group of professionals throughout their illness, and to be provided with information about their illness that was easy to understand.

6.6 Other additional suggestions of things that patients and carers find important are:

- Flexibility around the scheduling of appointments, especially for outpatients and radio- and chemo-therapy treatment, to fit around the working day (i.e. evenings and weekends);
- Making patients aware of the location of other soft tissue sarcoma centres to enable them to have a choice where possible;
- The routine availability of second opinions for pathology and radiology, and for treatment plans (perhaps up to three expert opinions?);
- Access to clinical trials;
- Training GPs to recognise suspected soft tissue sarcoma early on, and appropriate referral pathways;
- More single rooms for inpatients suffering from bad side-effects;
- Better hospital food;
- Single-sex wards;
- Age-related wards;
- Access to state-of-the-art equipment;
- All treatment to be undertaken at the same hospital where possible;
- Good, regular aftercare;
- Follow-up and regular treatment (e.g. radiotherapy) closer to home;
- Availability of hospital transport;
- Good communication between healthcare providers;
- Translation of treatment notes in other languages so patients and their families can confidently travel abroad.

6.7 Of the factors listed, the least important for patients and carers seemed to be (1) being treated in a place where their family and friends could be with them in private, (2) being treated in a place where family and friends can visit easily, (3) being provided with emotional support for themselves and their loved ones, and (4) being treated in a place close to where they lived.

6.8 It is anticipated that further patient/carer involvement will take place within the process to select the provider for each network, which will be via a competitive procurement process. The procurement will be divided into a specific tender for each individual network, with eligible providers restricted to the member organisations within the Network. Submissions from prospective providers will be tested against detailed evaluation criteria. Below we have identified the main evaluation criteria, and a range of topics covered within each.

Service delivery which includes:

- Clinical expertise
- The multidisciplinary team and its leadership and management
- Design and delivery of services e.g. diagnostic clinics and pathology, surgical treatment, rehabilitation, follow up and surveillance
- Physical facilities such as wards, theatres and other services, their quality and layout
- Patients experience and support to families

Quality and clinical governance:

- Clinical governance structures, policies and processes
- Risk monitoring and management
- Clinical standards and how they would be monitored
- Training and education
- Working in a network and linking with stakeholders
- Data and information for audit and outcomes
- Ensuring quality of access and outcomes
- Current quality standards performance including hospital acquired infections

General organisational readiness:

- Confirmation that the provider will meet required standards within required timescales
- Ensuring mature corporate behaviour in leading and managing the service

Affordability and value for money:

- Analysis of costs, prices, affordability and competitiveness

The full criteria will be finalised by the procurement evaluation panel who will consider the tenders received. As well as the review of written submissions they will visit potential providers and their services. The visiting team/panel will consist of:

- Surgeon with specialist expertise
- Pathologist with specialist expertise
- Specialised commissioning & finance representatives
- Patient & public representation
- Public Health

- Procurement/contracting

This work when completed will result in a final recommendation for the two preferred providers, which will be submitted to the Primary Care Trusts followed by overview and scrutiny committees for approval.

7 Current timescales

- 7.1 The procurement phase of the designation process is due to start in the autumn of 2009, and is due to be completed, with contracts awarded, in mid-December 2009 and services in place by March 2010.

8 Summary

- 8.1 The South West Specialised Commissioning Group has worked with clinicians and patients to consider the Improving Outcomes Guidance and develop a model of care and treatment that will provide the best possible care and treatment for the populations served by the two Networks hosted within the South West. The model will establish a robust care pathway and service provided by a multidisciplinary team delivering expert care to the populations within their network and working together to share expertise. The South West Specialised Commissioning Group will select the Centre by assessing which providers are best able to meet the requirements of the guidance and other requirements within the service specification.
- 8.2 Having developed the model of care and service with support from local and national clinicians, patients, carers and members of the public, the two Cancer Networks and the South West Specialised Commissioning Group the South West Specialised Commissioning Group (SW SCG) is now in a position to start the procurement process to select the two service providers that the SW SCG will recommend be designated.

9 Local Impact Information

- 9.1 The following information provides locality-specific information about where residents currently go for treatment. The impact of the recommendations about which providers should be designated as specialist centres will be provided in the Stage 2 proposal, which will be submitted to Overview and Scrutiny Committees once the South West Specialised Commissioning Group has completed the evaluation of those who bid to provide the service.
- 9.2 Patients from Torbay are currently treated by Plymouth Hospitals NHS Trust, or occasionally by Royal Devon & Exeter NHS Foundation Trust. The proposal reduces the number of sarcoma service providers in the south of the South West region to one, and therefore it is possible that patients from Torbay may need to travel further to access treatment from the chosen south area provider. However, a recent MORI survey carried out in the Peninsula in

May 2009 has confirmed that the majority of people surveyed are prepared to travel further to access specialised services if the result is improved outcomes.

- 9.3 Further local impact information will be available in the Stage 2 submission to overview and scrutiny committees once expressions of interest have been received and the South West Specialised Commissioning Group is able to work with local PCTs to determine the likely implications of designation decisions made in relation to each potential provider.

10 Next steps

- 10.1 The procurement phase is due to run from the autumn and into the winter of 2009. An advertisement for delivery of the service will be placed in Supply2Health inviting expressions of interest. Potential centres who wish to deliver the South West adult soft tissue sarcoma service will be asked to complete a self-assessment pre-qualifying questionnaire (PQQ), and if suitable will be issued with full service specification documents and an invitation to negotiate (ITN).
- 10.2 The Specialised Commissioning Group commissioners, alongside patient representatives and independent clinical representatives, will conduct formal interviews and visits of the potential providers following the receipt of tenders. Following this, a recommendation on the outcome will be referred back to Overview and Scrutiny Committees prior to designation being confirmed. We anticipate this work should be completed in line with the designation timetable.
- 10.3 If approval is given by the Specialised Commissioning Group, and endorsement is gained from Overview and Scrutiny Committees, the designation outcome report (that includes the implementation report) will be circulated to stakeholders. A notice that provides a summary of the outcome will also be placed in Supply2Health within 48 days of notifying providers they have been designated. We anticipate being able to issue contracts the spring of 2010.

11 Recommendation

- 11.1 The Torbay Overview and Scrutiny Committee is asked to:
- Note the proposed approach to providing soft tissue sarcoma services for their residents;
 - Note the improved quality and safety of service that their residents will receive;
 - Note the involvement of patients, clinicians and the public in the process to date;
 - Support the proposed approach, including the intention to designate two soft tissue sarcoma centres in the South West region, ready for service delivery in Spring 2010.