

Service Development for Soft Tissue Sarcoma Services for Adults Stage 2 OSC Briefing: For Information

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1 Purpose of the Report

- 1.1 To update Plymouth Health and Adults Overview and Scrutiny Committee on the outcome of the designation of soft tissue sarcoma services within the Peninsula. This briefing confirms the agreed arrangements for the Peninsula, which have the support of the National Cancer Action Team and the Peninsula Cancer Network as well as local hospital clinicians, GP Consortia and PCT commissioners.

2 Background

- 2.1 You may recall that the region's Overview and Scrutiny Committees supported the Specialised Commissioning Group's proposal to commence work to designate two specialised centres for Soft Tissue Sarcoma services for adults (one in the North of the South West, and one in the South) in August 2009.
- 2.2 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 tissues of the body (please see incidence figures overleaf). Signs and symptoms can vary greatly depending on the site of the tumour, as do treatment options and prognoses. Consequently, 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. The rarity of soft tissue sarcoma also means that 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. Hence, many sarcomas are discovered following a 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, if indicated, for specialist surgery.

**Incidence of Sarcoma (ICD-10 C48 or C49) 2007-09
 Adults (18 years or older at diagnosis)**

Area	PCTs	Cancer Network	Adult Population (2008)	Incidence (2007-09)
West of England	South Gloucestershire Bristol Teaching North Somerset Bath and North East Somerset Somerset Wiltshire (excl South Wiltshire)	Avon Somerset and Wiltshire	1,530,265	399
Peninsula	Cornwall and Isles of Scilly Plymouth Teaching Torbay Devon	Peninsula	1,340,641	344
Dorset	Dorset Bournemouth & Poole	Dorset	573,060	147
Swindon	Swindon	Thames Valley (part)	91,723	42
Gloucestershire	Gloucestershire	3 Counties (part)	462,411	116
Total for South West SHA (excluding Southern Wiltshire)			3,998,100	1,048
Total for South West Specialised Commissioning Group adult soft tissue sarcoma service planning (excludes Gloucestershire, Swindon, Dorset and Bournemouth & Poole and the South of Wiltshire (Salisbury))			2,870,907	743

2.3 Although the above table shows the number of people aged 18 and over that were diagnosed with a sarcoma in the three years between 2007-2009 to reflect national definitions of an 'adult', the Improving Outcomes Guidance that relates to this Soft Tissue Sarcoma service states that the service should be tailored to 24+ year olds. This is because teenagers and young adults (TYA) aged 16 to 24 years with sarcoma will be able to access a specialised service at various hospitals across the region that has recently been established specifically for TYA patients. Children up to (and including)

- 15 years old will receive the specialised aspects of their care from paediatric services (at the Bristol Royal Hospital for Children).
- 2.4 Both adult and paediatric cancer services will have a TYA service element to them to cater for young people. Long term patients would have had discussions as early as possible to prepare them for the transition into adult services and will be given the choice on their 19th birthday about whether they would like to transition to the adult service or remain a TYA patient.
- 2.5 When the designation process began adult patients from the Peninsula Cancer Network area (Cornwall and the Isles of Scilly, Plymouth, Torbay and Devon) were 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) were receiving their treatment from a combined service at North Bristol NHS Trust and University Hospitals Bristol NHS Foundation Trust. There was some informal communication and sharing of clinical ideas across the South West and with clinical teams in other areas, but no formal agreement or protocol for working together.
- 2.6 Designation of Sarcoma services was initially undertaken with the anticipation of designating one surgical centre within the Peninsula. This was based upon an agreement on responding to the requirements of the Improving Outcomes Guidance (IOG) and advice from the National Cancer Action Team (NCAT). However, since then the National Institute for Health and Clinical Excellence (NICE) has issued a set of peer review standards for sarcoma, which reinforces the role of the multidisciplinary team (MDT) and the importance of pathologists and surgeons with specialist skills and experience in sarcoma overseeing the care pathways of patients with soft tissue sarcoma. This has put considerably less emphasis on the need for fewer, larger surgical centres. Discussions with local commissioners and clinicians have also supported the SCG to consider whether a two centre 'partnership' option might be possible in the Peninsula, retaining the service on more than one site. We are delighted that this has now been achieved in the designation decision reached.

3 Outcome of the designation

- 3.1 In agreement with National Cancer Action Team, the South West Specialised Commissioning Group Board, local Primary Care Trusts (PCTs) and GP Consortia, we are now able to confirm the following:
- A single Multi-Disciplinary Team (MDT) will operate for patients within the Peninsula, across both Plymouth Hospitals and Royal Devon & Exeter sites. This arrangement will initially be led by Plymouth Hospitals NHS Trust. The lead Trust agreement will be kept under review, and leadership may move to the Royal Devon and Exeter NHS Foundation Trust in the future by mutual agreement.

- The joint MDT will be responsible for agreeing the appropriate treatment regime for individual patients, including the most appropriate hospital site for surgery, where appropriate.
 - The two Trusts will jointly develop, and work to, shared clinical protocols, together with supporting clinical audit arrangements. This will ensure that sarcoma diagnosis and treatment continues to be provided by clinicians who specialise in soft tissue sarcoma.
- 3.2 In line with the Improving Outcomes Guidance, NICE peer review standards and the results of an extensive programme of public and patient engagement that was completed early in the designation process (see <http://www.swscg.nhs.uk/consultation> for a summary report), a shared-care model will be encouraged for follow-up care and routine common treatment regimens (for example, chemotherapy). 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 team that are experts in soft tissue sarcoma.
- 3.3 As well as the functions of the MDT in dealing with individual patients, there are overall tumour site-specific co-ordinating functions needed by the sarcoma service across the whole South West Specialised Commissioning Group (SWSCG) area. As such, the MDT will be affiliated to the Sarcoma Advisory Group (SAG) that has been developed for the Peninsula. This means that parts of patients' care pathways can be received at other hospitals, potentially closer to where they live, whilst ensuring all aspects of their care are co-ordinated and overseen by a team that has met the necessary clinical standards. In terms of accountability and governance arrangements however, the MDT's relationship with the Peninsula SAG is crucial, as the SAG will be responsible in terms of peer review.
- 3.4 At the same time, we are developing a properly structured network across the South West that can provide training and advice to GPs, pathologists and general surgical hospital doctors. We would consequently expect increased awareness, more consistent treatment pathways and earlier diagnosis of soft tissue sarcoma. In this way we expect to achieve the following without reducing access to, nor moving the location of, specialised soft tissue sarcoma services in the Peninsula:
- Ensure the quality of clinical services
 - Increase early detection and accurate diagnosis of sarcoma
 - Ensure patients receive the highest quality sarcoma treatment delivered through multidisciplinary team co-ordination
 - Improve clinical outcomes and survival rates over time
 - Improve the patient experience through a stronger and clearer care pathway

- 3.5 This model of care has been received and endorsed by the National Cancer Action Team, the Peninsula Cancer Network and local clinicians, GP Consortia and commissioners.

4 Decisions/Actions Requested

4.1 Plymouth Health and Adults Overview and Scrutiny Committee is asked to:

- Note the proposed approach to providing soft tissue sarcoma services
- Note the involvement of patients, clinicians and the public in the process
- Note the improved quality and safety of service that the model will deliver over time

5 Glossary

Cancer Network	A group of professionals that help cancer services and organisations in the area to work together to reduce cancer rates and improve experiences and outcomes for patients.
Chemotherapy	Chemotherapy is a treatment used for some types of cancer. There are over 200 different types of cancer and over 50 chemotherapy drugs, which can be given in various ways.
Designation	Designation is a way of commissioning that involves commissioners working closely with local clinicians, patients, carers and members of the public to ensure designated providers meet recommended safety and quality standards. In this sense, designation is a quality assurance marker. Designation also prevents unsafe or wasteful duplication of specialised services, by formally designating an appropriate number of service providers to serve a Specialised Commissioning Group (SCG) population, that are best placed to provide high quality and best value services.
Improving Outcomes Guidance	The Improving Outcomes series of guidance was started by the Department of Health under the auspices of the NHS Executive in 1996 and handed over to the National Institute for Health & Clinical Excellence (NICE) in 2000. Each set of guidance sets out ways for improving the treatment that patients of a particular service receive.
Multi-Disciplinary Team	Group of experts from many different specialities working together to deliver a package of care.
National Cancer Action Team (NCAT)	A multidisciplinary team working with the Department of Health as part of the Cancer Reform Strategy's drive to improve cancer services and reduce inequalities in the provision of cancer care.

NICE	NICE (National Institute for Clinical Excellence) is an independent organisation responsible for providing national guidance on promoting good health and preventing and treating ill health.
Pathologist	Pathologists are scientists that study and diagnose disease, often through examining tissue samples.
Peer Review Standards	Peer review is a process of self-regulation by a profession or a process of evaluation involving qualified individuals within the relevant field. Peer review methods are employed to maintain standards, improve performance and provide credibility.
Peninsula	The Peninsula refers to the geographical area served by Devon, Cornwall & Isles of Scilly, Torbay and Plymouth Primary Care Trusts.
Prognoses	Predictions about how a disease is likely to progress or respond to treatment.
Public & Patient Engagement	As part of the commissioning/designation commissioners will seek the views of patients, carers and members of the public to develop service specifications and commissioning plans that help the health sector meet future challenges.
SCG	Specialised Commissioning Group (SCG) is comprised of all the Primary Care Trusts in a given geographical area that come together to commission specific group of services that have been defined as specialised. Currently, there are 10 SCGs in England, all with the same boundaries as the Strategic Health Authorities that oversee their work.
Shared Care	The responsibility for appropriate long-term medical care must be shared by cancer survivors, their families, the oncology team, and primary care providers.
Soft Tissue Sarcoma	A cancer that begins in the muscle, fat, fibrous tissue, blood vessels or other supporting tissue of the body. It is a rare cancer that accounts for

	about 1% of all malignant tumours. The cause of most cases of soft tissue sarcoma is not known. However there are certain risk factors for the development of soft tissue sarcomas.
Specialised Services	Specialised services generally involve complex procedures or require very specialised workforce and or treatment/ care for conditions that are rarer than those treated in local hospital. Consequently, specialised services often serve a wider population catchment than do local services and are not available in every hospital.
Stakeholders	Stakeholders refer to any person who has a stake and interest in the services that commissioners plan, designate and procure. Stakeholders can be professionals, patients, carers, members of the public, volunteers.
Treatment Regimen	Systematic course of therapy.