

# **NATIONAL OPTIMAL PATHWAY FOR SARCOMA CANCER: 1<sup>st</sup> EDITION (2024)**

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## **Point of Suspicion to First Definitive Treatment in Adults (aged 16 and over)**

<b>Date of Issue: February 2024</b>
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<b>Owner: Sarcoma Cancer Site Group</b>

# FOREWORD

The NHS Wales National Optimal Pathways (NOPs) have been developed as part of the Suspected Cancer Pathway (SCP) programme of work. They aim to establish consistent generic and site-specific pathways that describe all routes of entry, from the point of suspicion (PoS) of cancer. They describe good practice diagnostic and treatment pathways, the diagnostic pathway, including staging, should be performed within 28 days from PoS; and definitive treatment commenced within 21 days from date of Decision to Treat (DTT). The pathways also describe where patients should receive consistent information and support, tailored to meet their needs.

The NOPs aim to provide a platform to standardise care, reduce unwarranted variation and drive improvement whilst increasing quality across each of the cancer pathways in order to:

- meet the SCP cancer waiting time of 62 days for patients presenting with a suspicion of cancer,
- improve cancer patient experience, and,
- improve cancer patient outcomes throughout Wales to that comparable with the best outcomes in Europe.

The Sarcoma Cancer NOP is designed to help sarcoma cancer service providers and their commissioners understand the structure of an effective and efficient sarcoma cancer pathway. In essence, this optimal pathway is about ensuring that each stage of the pathway happens in a timely manner, that patients are communicated with about their treatment, care and needs, and that the entire team works in a coordinated but flexible way, focusing always on the patient's journey. It is recognised that the introduction of the National Optimal Pathway for Sarcoma Cancer may present challenges for the sarcoma cancer multidisciplinary teams. However, introducing a nationally agreed, clinically endorsed pathway will support service improvement. This will also provide clarity and consistency for primary care around the referral process into secondary care, including access to diagnostics, to ensure that patients move through the system in a timely manner.

## GROUP CONSULTATION

The pathway development was led by Johanne Vass, Macmillan Sarcoma Advanced Nurse Practitioner at Swansea Bay University Health Board, Joanne Gronow, Sarcoma Clinical Nurse Specialist at Velindre NHS Trust and Mr Thomas Bragg, Consultant Surgeon at Swansea Bay University Health Board. In 2021 meetings with relevant stakeholders allowed for the initial draft version of the NOP to be circulated for consultation and incorporate the feedback gathered. Since then, further work on the NOP and genomics pathway took place in 2023, for the NOP to be re-circulated for a second round of consultation amongst relevant stakeholders, with submission to Cancer Network Board in January 2024.

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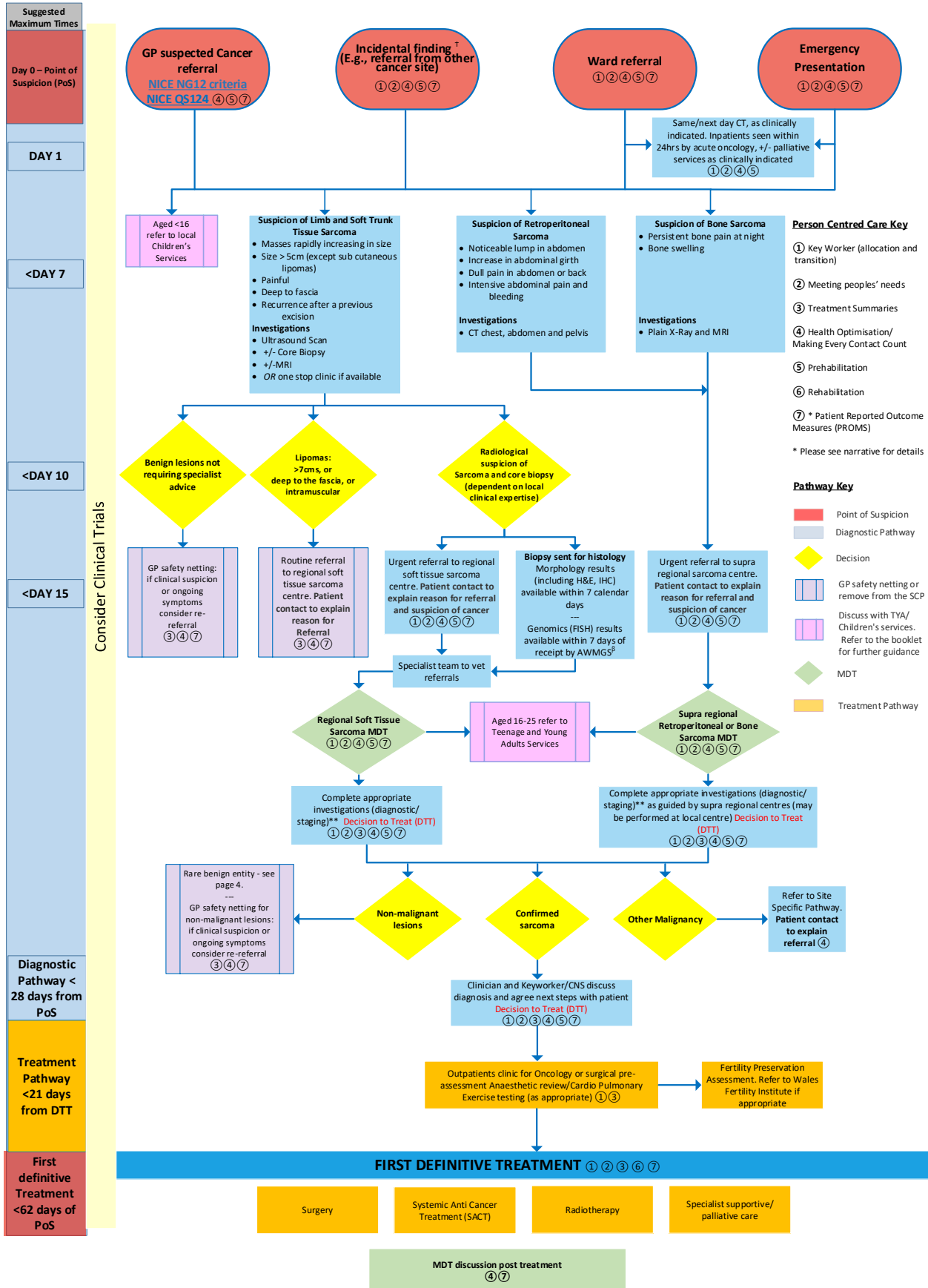
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**Date 17/01/2024**

# NATIONAL OPTIMAL PATHWAY FOR SARCOMA: Point of Suspicion (PoS) to First Definitive Treatment (FDT) in Adults (aged 16 and over)



<sup>†</sup> Refer to annex 1 PoS (page 21) - <https://www.gov.wales/suspected-cancer-pathway-guidelines-whc202218>

\*\*WHSC Commissioning Policy: Positron Emission Tomography (PET) - <https://whsc.nhs.wales/commissioning/whsc-policies/all-policy-documents/positron-emission-tomography-pet-commissioning-policy-cp50a-april-2023/>

<sup>§</sup> AWMGS - Cymru Service for Genomic Oncology Diagnoses (CYSGODI) (<https://medicalgenomics.wales.co.uk>)

## Sarcoma Tumour Pathway

- Sarcomas are a rare and diverse group of cancers thought to have a common embryological origin.
- They arise from cells that comprise the connective tissue structure, including bone, cartilage, muscle, blood vessels, nerves and fat. They can occur almost anywhere in the body.
- Sarcomas can be broadly divided into those of bone and those of soft tissue.
- Referral pathways for people diagnosed with **soft tissue sarcoma** are as follows:
  - South Wales – Soft tissue sarcoma MDT, Swansea Bay University Health Board
  - North Wales – Greater Manchester and Oswestry Adult Sarcoma MDT, Manchester Hospitals Foundation Trust
- Referral pathways for people diagnosed with **retroperitoneal sarcoma** are as follows:
  - South Wales – Regional Soft Tissue Sarcoma MDT, University Hospital Birmingham
  - North Wales - Greater Manchester and Oswestry Adult Sarcoma MDT, Manchester Hospitals Foundation Trust
- Referral pathways for people diagnosed with **bone sarcoma** are as follows:
  - South Wales – The Royal Orthopaedic Hospital Bone Tumour Service
  - North Wales – The Robert Jones and Agnes Hunt Orthopaedic Hospital NHS Foundation Trust
- Due to the complex nature of this cancer, early contact with the MDT lead and nurse specialists and Allied Health Professionals is welcomed, in order to provide timely guidance and support.
- Service standards should comply with the Welsh Health Specialised Services Committee specialised services specification CP149 (<https://whssc.nhs.wales/commissioning/whssc-policies/cancer/soft-tissue-sarcoma-service-specification-cp149-june-2020/>).
- Patients will remain under the care of the referring consultant or nominated health board lead for sarcoma until the MDT accepts and takes over care. Clear lines of communication must be established and shared between the sarcoma MDT, referring clinician, the patient and their GP. The Sarcoma MDT should make it clear who is responsible for any further care or management, including who is taking responsibility for any investigations that need to be performed (taken from WHSC Soft Tissue Sarcoma Service Specification, cp149, June 2020).
- Genomic testing using FISH (in line with the NHS England National Genomic Test Directory for Cancer) is available via AWMGS in cases where specialist sarcoma pathology review indicates that molecular assessment will aid diagnosis or management. Results will be made available to the reporting pathologist for integration into the diagnostic histology report.
- Desmoid Fibromatosis (DF) and other soft tissue tumours (rare benign entities) will often be diagnosed as a result of assessment in a sarcoma diagnostic service. Biopsy is usually necessary to confirm the diagnosis.
- At diagnosis or suspected diagnosis, all patients with suspected DF must be referred to the Specialist Sarcoma MDT for advice regarding diagnosis and management.
- In the event of disease progression then different treatment options are available. Clinicians supervising the care of sarcoma patients should seek the advice of the Sarcoma MDT after discussion with the patient and be in accordance with UK and international guidelines.
- Soft tissue sarcomas requiring shared management include:
  - Gynaecological sarcoma – these are usually diagnosed post operatively and should be immediately referred to the sarcoma MDT
  - Head & neck sarcoma – Head & neck and sarcoma MDTs should work jointly to ensure patients can access all necessary expertise and support
  - Chest wall/intrathoracic sarcoma – care plans should be confirmed by a sarcoma MDT and treatment delivered in designated services
  - Skin sarcoma – Dermatology and Sarcoma MDTs should work jointly to ensure patients can access all necessary expertise and support
  - Gastro-intestinal stromal tumours (GIST) – patients with GIST should have their care/treatment plan confirmed by a specialist GIST or upper GI MDT and have treatment delivered by services designated by that MDT

- Breast sarcoma – people with suspected breast sarcoma should be referred to a sarcoma MDT and treatment delivered by services designated by that MDT
- Cardiac/large vessel sarcomas - Intimal sarcomas and angiosarcomas of the heart and great vessels are a rare entity demanding specific multidisciplinary expertise in order to consider the options for an individual of combined modality treatment, including cardiac surgery
- The care of patients with soft tissue sarcomas requiring shared management should be managed by the appropriate site-specific MDT or the MDT for children in conjunction with the sarcoma MDT
- The site-specific MDT has primary responsibility to liaise with the sarcoma MDT to discuss the management of each patient.
- For children and young patients, refer to the children's sarcoma pathway.
- All TYA patients diagnosed with sarcoma should be referred to the TYA MDT in parallel for psychosocial support.

## BEST PRACTICE GUIDANCE

<b>Transfer of histology specimens</b>	Initial processing and immunostaining of samples performed at referring hospital. Specimens should then be sent without delay to the soft tissue histopathologists in SBUHB.
<b>Staging and surveillance</b>	<p>It is recommended that patients diagnosed with myxoid liposarcoma are initially staged with CT thorax and whole-body MRI, with annual whole-body MRI surveillance for early identification of extrapulmonary metastases. PET CT is recommended ahead of highly morbid surgery where multifocal metastases would change management, staging sarcoma subtypes associated with unpredictable patterns of metastatic disease and to characterise nodal disease and inform biopsy of heterogenous tumours.</p> <p>It is recommended that staging CT/MRI investigations are performed within 72 hours of MDT review.</p> <p><a href="https://www.whssc.nhs.wales/commissioning/whssc-policies/all-policy-documents/positron-emission-tomography-pet-commissioning-policy-cp50a-april-2023/">whssc.nhs.wales/commissioning/whssc-policies/all-policy-documents/positron-emission-tomography-pet-commissioning-policy-cp50a-april-2023/</a></p>
<b>Physiological optimisation</b>	It is recommended that if diagnostic investigations (radiology) identify a suspected cancer, that teams give thought to patient fitness optimisation to run concurrently with pathological staging investigation. This could include consideration of the need for respiratory or cardiology (e.g. echocardiogram) investigation.
<b>Preservation of tissue for genomics</b>	It is recommended that the preservation of tissue for genomic testing is taken into account when preparing the initial biopsy sample. Optimal fixation time for genomics requires the specimen not be in formalin for more than 24 hours. Cutting sections up front, (to reduce waste at the microtome) and/or splitting the material over more than one block may also reduce the amount of waste at the microtome (as well as speeding up subsequent requests). Each Health Board can identify their own practice for this that is suited to local arrangements.

# DEFINITIONS

<b>Decision to Treat</b>	<p>The DATE on which a <b>Decision to treat</b> is made. For the cancer data sets, the <b>Decision to treat</b> DATE is the DATE that the consultation between the PATIENT and the clinician took place and a Planned Cancer Treatment was agreed.</p> <p>Source: <a href="https://datadictionary.nhs.uk">NHS Data Model and Dictionary (datadictionary.nhs.uk)</a></p>
<b>Direct to Test</b>	<p>GPs have direct access to diagnostic ultrasound, MRI, X-ray and CT for people suspected of cancer.</p> <p>Source: <a href="#">National Institute for Health and Care Excellence, Quality Standard 2016 (QS 124)</a></p>
<b>First Definitive Treatment</b>	<p><b>First Definitive Treatment</b> is the <b>first</b> CLINICAL INTERVENTION intended to manage a PATIENT's disease, condition or injury and avoid further CLINICAL INTERVENTIONS. What constitutes <b>First Definitive Treatment</b> is a matter of clinical judgement in consultation with others, where appropriate, including the PATIENT.</p> <p>Source: <a href="https://datadictionary.nhs.uk">NHS Data Model and Dictionary (datadictionary.nhs.uk)</a></p>
<b>Safety Netting</b>	<p>"Safety netting is a management strategy of patients, tests and referrals used in the context of diagnostic uncertainty in healthcare. It aims to ensure patients are monitored until signs and symptoms are explained or resolved."</p> <p>Source: <a href="#">Royal College of General Practitioners (RCGP) - Home</a></p>
<b>Straight to Test</b>	<p>Following clear referral criteria into secondary care (usually NICE guidance) the secondary care clinician (defined as per local protocol) will arrange a diagnostic procedure as the first episode of care in place of an outpatient episode. The clinician will retain clinical responsibility for the result including acting on the result, and onward referral to an MDT where appropriate.</p> <p>Source: <a href="#">Delivering Cancer Waiting Times NHSE</a></p>
<b>Teenagers and Young Adults (TYA) Service</b>	<p>Young people (aged 16-24 years) with cancer have their diagnosis treatment and support agreed and delivered by a cancer-site specific multidisciplinary team and a teenage and young adult multidisciplinary team.</p> <p>Source: <a href="#">National Institute for Health and Care Excellence (NICE), 2014. Cancer services for children and young people (QS55)</a></p> <p><a href="#">STANDARD FOR TEENAGERS AND YOUNG ADULTS WITH CANCER (nhs.wales)</a></p>

# CLINICAL EVIDENCE

<b>Point of Suspicion/Referral</b>	<p>The point of suspicion is when a clinician refers a patient or requests a test concerns a patient may have cancer. Pathway start dates are defined in the following guidance:</p>
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	<p><a href="#">Single Suspected Cancer Pathway Definitions (December 2018)</a></p> <p>Additional information:</p> <p><a href="#">Cancer Risk Assessment Tool (RAT)</a></p> <p><a href="#">Q Cancer Risk Assessment Tool</a></p> <p><a href="https://cks.nice.org.uk/topics/bone-soft-tissue-sarcoma-recognition-referral/">https://cks.nice.org.uk/topics/bone-soft-tissue-sarcoma-recognition-referral/</a></p>
<b>Diagnosis and Management</b>	<p>BSG Ultrasound Screening of Soft Tissue Masses in the trunk and extremity: a British Sarcoma Group guide for ultrasonographers and primary care; January 2019:</p> <p><a href="#">Microsoft Word - BSG guidance for ultrasound screening of soft tissue masses in the trunk and extremity (britishsarcomagroup.org.uk)</a></p> <p>NICE Quality Standard; Sarcoma; 29<sup>th</sup> January 2015:</p> <p><a href="#">Sarcoma (nice.org.uk)</a></p> <p>UK Guidelines for the management of soft tissue sarcomas:</p> <p><a href="#">UK guidelines for the management of soft tissue sarcomas   Clinical Sarcoma Research   Full Text (biomedcentral.com)</a></p> <p>Welsh Health Specialised Services Committee; Specialised Services Service Specification CP149; May 2020:</p> <p><a href="https://whssc.nhs.wales/commissioning/whssc-policies/cancer/soft-tissue-sarcoma-service-specification-cp149-june-2020/">https://whssc.nhs.wales/commissioning/whssc-policies/cancer/soft-tissue-sarcoma-service-specification-cp149-june-2020/</a></p>

## PERSON CENTRED CARE

Person-centred cancer care is culturally embedded and supported by a common approach to assessing and managing people's needs, and care should be co-produced to ensure people affected by cancer achieve the outcomes that matter to them (Cancer Quality Statement, 2021).

<b>Key Worker</b>	<p>QS 14: Patients are made aware of who to contact, how to contact them and when to make contact about their ongoing healthcare needs. <a href="#">National Institute for Health &amp; Care Excellence (NICE, 2012) CG138 Clinical Guideline: Patient Experience in adult NHS services</a></p> <p><i>A cancer key worker is "a person who, with the patient's consent and agreement, takes a key role in coordinating the patient's care and promoting continuity, ensuring the patient knows who to access for information and advice".</i></p> <ol style="list-style-type: none"> <li>1. All cancer patients must have an allocated key worker.</li> <li>2. Allocation / Review of key worker to take place at key time points including: <ol style="list-style-type: none"> <li>a. Around the time of diagnosis <i>*please note: allocation of key worker <b>may</b> occur earlier than time of diagnosis, if there is a very high level of suspicion of cancer e.g. evidence obtained via pathology, radiology.</i></li> <li>b. Commencement of treatment</li> </ol> </li> </ol>
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	<p><a href="#">Key workers for cancer patients (Welsh Health Circular /2014/001) GOV.WALES</a></p> <p><a href="#">Cancer Improvement Plan for Wales</a></p>
<b>Meeting People's Needs</b>	<p>QS 4: Patients have opportunities to discuss their health beliefs, concerns and preferences to inform their individualised care.</p> <p>QS 10: Patients have their physical and psychological needs regularly assessed and addressed, including nutrition, hydration, pain relief, personal hygiene and anxiety. <a href="#">National Institute for Health &amp; Care Excellence (NICE, 2012) CG138 Clinical Guideline: Patient Experience in adult NHS services</a></p> <p>Assessment and discussion of patients' needs for physical, psychological, social, spiritual and financial support should be undertaken at key points including:</p> <ul style="list-style-type: none"> <li>• Around diagnosis <i>*please note: undertaking a Holistic Needs Assessment <b>may</b> occur earlier than time of diagnosis, if there is a very high level of suspicion of cancer e.g. evidence obtained via pathology, radiology, endoscopy; and it is supported by professional judgement.</i></li> <li>• At commencement, during, and at the end of treatment</li> </ul> <p><a href="#">National Institute for Clinical Excellence (NICE, 2004) CSG4 Improving Supportive &amp; Palliative care for adults with cancer</a></p> <p>Ideally Holistic Needs Assessments should be undertaken electronically (<a href="#">Cancer Improvement plan for Wales/</a>). Macmillan eHNA is <i>one</i> tool which is both valid and reliable. <a href="#">Snowden A &amp; Fleming M (2015) Validation of the electronic HNA.</a></p> <p>Where appropriate, the impact of the cancer and its treatment on future fertility should be discussed with the cancer team at the earliest opportunity. The eligibility criteria for treatment are set out in the WHSSC Specialist Fertility Commissioning Policy, CP38 (link below). Opportunity should be provided to explore any individual concerns and address any unmet needs and early speciality referral should also be offered.</p> <p><a href="http://whssc.nhs.wales/commissioning/whssc-policies/fertility/specialist-fertility-services-commissioning-policy-cp38-feb-2020/">whssc.nhs.wales/commissioning/whssc-policies/fertility/specialist-fertility-services-commissioning-policy-cp38-feb-2020/</a></p>
<b>Health Optimisation / MECC</b>	<p>QS 9: Patients experience care that is tailored to their needs and personal preferences, taking into account their circumstances, their ability to access services and their coexisting conditions.</p> <p><a href="#">National Institute for Health &amp; Care Excellence (NICE, 2012) CG138 Clinical Guideline: Patient Experience in adult NHS services</a></p> <p>Health Optimisation refers to a proactive approach to supporting people who present to NHS services with concurrent comorbid health conditions (e.g. anaemia, diabetes), or health risk behaviours (e.g. smoking, physical inactivity).</p> <p><a href="#">Welsh Government (2018) A Healthier Wales.</a>  <a href="#">Welsh Government (2015) Wellbeing of Future Generations Act.</a></p> <p>Patients should undergo an objective assessment of peri-operative risk to help inform peri-operative care requirements. They should also have access to peri-operative optimisation</p>



	<p>resources such as nutritional support, smoking cessation advice, exercise prehabilitation and intravenous iron.</p> <p>Making Every Contact Count (MECC) is a behaviour change approach that helps health and social care professionals support people to improve their health and wellbeing through prevention and early intervention. <a href="#">Public Health Wales Strategic Plan 2023-2026</a></p> <p><b><i>Lifestyle advice / resources are available from <a href="#">Making Every Contact Count</a> (MECC)</i></b></p> <p><i>*Please note: Whilst addressing concurrent comorbidities and health risk behaviours is the responsibility of <b>all</b> health and social care professionals, at <b>every</b> contact throughout the pathway; earliest possible intervention <b>may</b> impact on cancer treatment choices / outcomes (especially in respect to tobacco smoking). <a href="#">National Institute for Clinical Excellence (NICE, 2018) NG92 NICE Guideline Stop Smoking Interventions and services.</a></i></p>
<b>Prehabilitation</b>	<p>All patients should be given multimodal prehabilitation advice and support covering physical activity, emotional wellbeing, eating well, stopping smoking and reducing alcohol intake prior to undergoing treatment in order to enhance patient outcomes. Patient needs and goals should be evaluated on an individual basis and appropriate levels of support, from universal self-management advice to specialist support which includes timely access to allied health professional should be provided.</p> <p>Patients should have the opportunity to take part in evidence-based education and rehabilitative activities, including self-management programmes, <i>where available</i>, that promote their ability to manage their own health if appropriate.</p> <p><a href="#">National Institute for Health &amp; Care Excellence (NICE, 2012) CG138 Clinical Guideline: Patient Experience in adult NHS services</a>  <a href="#">Welsh Government (2018) A Healthier Wales.</a>  <a href="#">Welsh Government (2015) Wellbeing of Future Generations Act.</a>  <a href="#">The Quality Statement for Cancer.</a></p>
<b>Rehabilitation</b>	<p>All patients will have their needs for rehabilitation services assessed, with referral to an appropriate level of rehabilitative support, throughout the patient pathway including timely access to allied health professional to meet individual holistic patient needs and goals.</p> <p><i>*Please note: not <b>all</b> patients will require specialist cancer rehabilitation services. Referral into non-cancer rehabilitation, self-management, and fitness services <b>may</b> be suitable to meet some patients' needs.</i></p> <p><a href="#">National Institute for Health and Care Excellence (NICE) CSG4 (2004) resources for improving supportive and palliative care for adults with cancer.</a></p>
<b>Patient Reported Outcome Measures (PROMs) / Patient Reported Experience Measures (PREMs)</b>	<p>Patient Reported Outcome Measures (PROMs) are questionnaires that patients are asked to complete <b>before</b> and <b>after</b> treatment to assess the impact on health and wellbeing.</p> <p><b>Some</b> of the Cancer Site Groups (CSGs) have been working with the International Collaboration for Health Outcome Measurement (ICHOM), Value Based Healthcare Team, <a href="#">National PROMS, PREMS, &amp; Effectiveness Programme</a> (NPP&amp;EP) and other partners, to pilot tools and data capture methods, which will inform a consistent approach to PROMS &amp; PREMS for cancer. <a href="#">The Quality Statement for Cancer</a></p> <p><i>*Please note: there are outstanding questions relating to tool selection, data capture intervals, data capture methods and data analysis / reporting which <b>may</b> prevent the implementation of PROMS &amp; PREMS across all pathways at this time. PROMS &amp; PREMS have</i></p>

	<p><i>been included in the pathways, in recognition of this work, and will be updated pending further advice from the CSGs.</i></p> <p>Patient Reported Experience Measures (PREMs) are questionnaires that patients are asked to complete at <b>any time</b> during their pathway to help professionals to understand their experience of NHS services. This information is crucial to understanding the value of healthcare as perceived by patients. <a href="#">Welsh Government (2018/19). Chief Medical Officer Annual Report.</a></p> <p><i>*Please Note: Whilst it is good practice to collect PREMS throughout the pathway, there is no current standard for cancer PREMS in Wales; further advice regarding this will be sought via the CSGs in due course.</i></p>
<b>Communication</b>	<p>Clinicians must ensure patients are kept up to date about their care pathway and are supported to make individualised choices about their treatment.</p> <p>Clinicians should consider the value of interventions and discuss with the patient the likely outcome of treatment options.</p> <p>Clinicians in secondary and tertiary care must ensure that all decisions relating to a patient's care or treatment are communicated to the patient and their primary care clinician in a timely manner and within 24 hours of diagnosis.</p> <p>Clinicians must ensure that the clinical intention of any intervention such as tests or treatment is clear to patients, and whether it is just a stage of the agreed pathway or considered start of first definitive treatment and as such ends the pathway.</p> <p>Clinicians must make contemporaneous records of discussions and decisions and include reasons for deviations from recommended clinical practice in the patient's clinical record. Decisions should be made in a timely manner, and any onward referrals be completed promptly, according to local/national guidelines and optimal pathways and include adequate information to allow the receiving clinician to initiate appropriate interventions with the minimum of delay. Referrers must ensure that the patient is aware and is in agreement for a suspected cancer referral to be made.</p> <p><a href="#">Suspected cancer pathway: guidelines (WHC/2023/025)   GOV.WALES</a></p> <p>A treatment summary is a tool to improve communication between cancer services, primary care, and cancer patients. The treatment summary document is produced by secondary care and contains information about a patient's cancer history (e.g., diagnosis and treatment).</p>
<b>Research</b>	<p>Patients should have the opportunity to take part in research and clinical trials where available.</p> <p><a href="#">People in research   Health Care Research Wales (healthandcareresearchwales.org)</a></p> <p><a href="#">EC Trial Finder   ECMC (ecmcnetwork.org.uk)</a></p>