



NATIONAL OPTIMAL PATHWAY FOR COLORECTAL CANCER: 2nd EDITION (2023)

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

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Owner: Lower GI Cancer Site Group

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 Colorectal Cancer NOP is designed to help colorectal cancer service providers and their commissioners see the basic structure of an effective and efficient colorectal cancer pathway. In essence, this optimal pathway is about ensuring that each stage of the pathway happens quickly, that communications with patients are effective 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 Colorectal Cancer may present challenges for the colorectal cancer multidisciplinary teams. However, introducing a nationally agreed, clinically endorsed pathway will support service improvement. It will also provide clarity and consistency for primary care around the referral process into secondary care, including access to diagnostics, to ensure the patients move through the system in a timely manner.

GROUP CONSULTATION

The Colorectal Site Group (CSG) is led by Mr Martyn Evans, Consultant Colorectal Surgeon. The group includes representation from the full range of professions involved in delivering cancer services. They were all able to contribute and comment on the development of the optimal pathway during a range of pathway workshops, CSG meetings and educational days, commenced in January 2018. An early draft was sent to multi-disciplinary teams (MDTs), Health Boards and Velindre NHS Trust in August 2018. Separate workshops were also held with the Clinical Nurse Specialist (CNS) and Allied Health Professional (AHP) members to embed the Prehabilitation, Rehabilitation and Person-Centred Care (PCC) into the pathway, ensuring all patient's needs are assessed and met in a timely manner. Wider consultation was sought in May and June 2019 from NHS Wales's stakeholders, including National Imaging and Pathology Networks and the Third sector, over 70 responses were received and these were all carefully considered during the revision process, prior to a final version being issued in July 2019.

This second edition (2023) of the NOP reflects the changing developments in the treatment of colorectal cancer since the initial version was first described. Further guidelines around the usage of symptomatic Faecal Immunochemical Test (FIT) have been developed and published in a hope to move towards more streamlined triage and vetting when referrals go to secondary care, and to avoid referring patients that do not require secondary care input.

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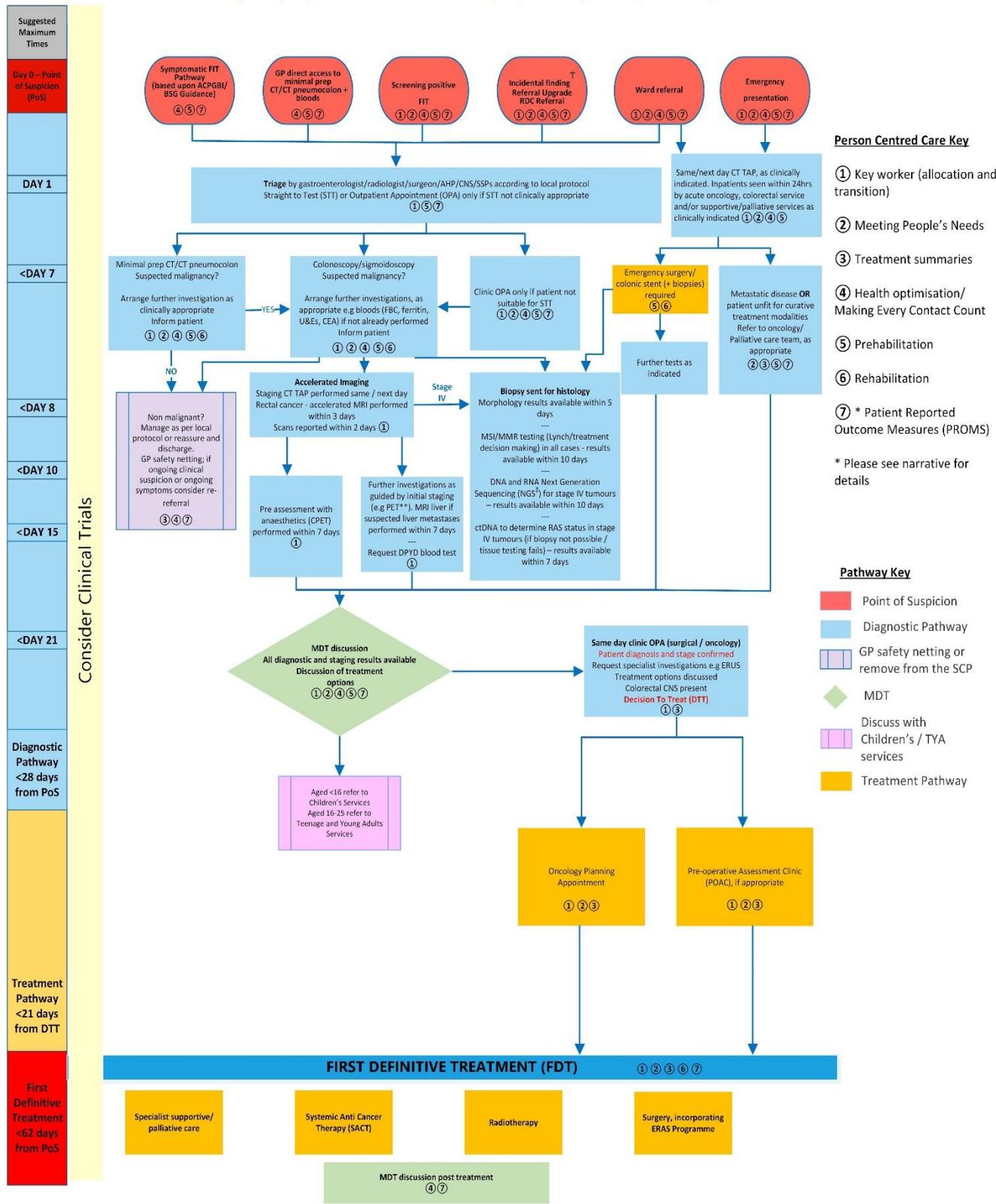
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Date 09/11/2023

National Optimal Cancer Pathway for suspected and confirmed Colorectal Cancers:
Point of Suspicion (PoS) to First Definitive Treatment (FDT) for adult patients (16 and over)



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

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

β AWMGS - Cymru Service for Genomic Oncology Diagnoses (CYSGODI) (<https://medicalgenomicswales.co.uk>)

BIOMARKER TESTING

All patients with a new diagnosis of colorectal cancer, regardless of stage or planned treatment, should be offered molecular testing to identify tumours with deficient DNA mismatch repair which may identify people in whom the cancer has occurred because of Lynch syndrome. [NICE diagnostics guidance DG27](#) recommends either immunohistochemistry for mismatch repair (MMR) proteins (via pathology laboratories) or microsatellite instability (MSI) testing (via the All Wales Medical Genomics Service (AWMGS)) to guide further sequential testing for Lynch Syndrome.

Health Board colorectal MDTs must have an agreed method for testing and ensure results are reviewed and acted upon, with onward referral to Clinical Genetics where appropriate. Patients should be informed of the possible implications of test results for both themselves and their relatives, ensuring relevant support and information is available.

Colorectal cancer patients with MSI-high or MMR deficient tumours may be eligible for non-chemotherapy based systemic anticancer therapy, depending on disease stage.

Stage IV tumours should be tested with both DNA and RNA Next Generation Sequencing (NGS) to guide systemic anticancer treatment decision-making. Please note this testing aims to identify somatic (acquired) variants rather than inherited (germline) variants. Test request forms are available via [AWMGS](#) and should be directed to the pathology laboratory housing the tissue specimen to be tested; requests should not be directly sent to AWMGS. Circulating tumour DNA (ctDNA) testing (using a blood sample) to detect RAS variants is available when either a biopsy is not possible or where the tumour specimen has been exhausted or molecular testing has failed.

SYMPTOMATIC FAECAL IMMUNOCHEMICAL TESTING

The Faecal Immunochemical Test (FIT) can identify possible colorectal cancer by detecting small amounts of blood (globin component of haemoglobin) in stool samples. It measures the faecal haemoglobin (Hb) concentration as microgram of Hb per gram ($\mu\text{g/g}$) of faeces. In symptomatic patients, a positive FIT is a result of $\geq 10\mu\text{g Hb/g}$, processed in an UKAS ISO 15189 accredited laboratory.

FIT has a superior positive predictive value for colorectal cancer over symptoms alone¹. It has a similar diagnostic accuracy in both high and low risk symptomatic patients, including younger age groups where there is an increasing incidence of colorectal cancer¹.

At the time of publication of the first version of the National Optimal Pathway for Colorectal Cancer (NOPCC) in 2019, the recommended use of FIT was limited to people with low risk symptoms². Subsequent to the new joint national guideline by the Association of Coloproctology of Great Britain and Ireland and British Society of Gastroenterology¹, this pathway outlines the integration of symptomatic FIT into the NOPCC. It also follows the recently published NICE guidance which can be found here - [Overview | Quantitative faecal immunochemical testing to guide colorectal cancer pathway referral in primary care | Guidance | NICE](#).

General Principals

- We recommend that FIT is available to all General Practices to support the assessment of people presenting with signs or symptoms raising the suspicion of colorectal cancer and as an adjunct to clinical history, examination (including anorectal examination) and appropriate blood tests (e.g. FBC, ferritin)
- We recommend that FIT is undertaken within primary care **prior** to considering referral in people presenting with signs or symptoms suspicious of colorectal cancer
- In some cases, there may be an ongoing high suspicion of colorectal cancer based upon symptoms and clinical judgement ('gut instinct') in people with a negative FIT. Referrals should clearly outline why cancer is still suspected

- We recommend that the use of FIT should be carefully considered in people potentially unsuitable for onward diagnostic investigation
- We recommend that direct/straight to test investigation is undertaken in people who are FIT positive. Where there is uncertainty regarding suitability for investigation (e.g. frailty or significant comorbidity), referrals should clearly outline this to support decision making in the triage of referrals in secondary care
- The Bowel Screening Wales (BSW) programme is available for asymptomatic participants, with a current FIT threshold of 150µg Hb/g and plans to reduce this to 80µg Hb/g in the future. This compares with a symptomatic FIT threshold of ≥10µg Hb/g. Therefore, we advise that FIT is undertaken in people presenting with signs or symptoms of suspected colorectal cancer at any time point, even following a negative bowel screening programme test. The point of suspicion (POS) for referrals from bowel screening is defined as the ‘Date that the lab validate a positive FIT test’.

Criteria

- We recommend that FIT is undertaken in people presenting with signs or symptoms suspicious of colorectal cancer (see flow chart below for guidance related to use of FIT in people with Iron Deficiency Anaemia)^{1, 3}
- We recommend that patients with an abdominal mass suspicious of malignancy should have a FIT undertaken alongside investigation (e.g. CT abdomen) or referral
- ACPGBI/BSG advise that a FIT is not required for patients with anal ulceration or anal/rectal mass prior to referral
- There is no indication for FIT in people with upper GI symptoms (e.g. dyspepsia)

Point of Suspicion

A clinical suspicion of cancer may result from:

- Positive FIT result (≥10µg Hb/g)
- Ongoing high clinical suspicion of colorectal cancer in patients with a negative FIT
- Clinical suspicion of cancer in patients unable to complete (e.g. due to physical disability) or declining FIT. The reason for an absent FIT test should be outlined in referrals to secondary care

First clinical suspicion of cancer	Recording the patient’s entry onto the single cancer pathway – day 0	Pathway entry
Referral from primary care: <ul style="list-style-type: none"> • Positive FIT stool test (≥10µg Hb/g) • High clinical suspicion of colorectal cancer in FIT negative patients or those unable to complete/declining FIT 	Date referral is sent from primary care to the Health Board	Referral from GP
Positive FIT stool test (≥10µg Hb/g) in secondary care e.g. outpatient clinic, inpatient, emergency presentation	Date the lab validate a positive FIT test result	Referral following diagnostic - Other

Referrals and Safety Netting

Waiting times across all referral priorities including suspected cancer have been impacted by the COVID pandemic. Robust safety netting advice is therefore imperative across primary and secondary care for patients who are FIT negative or where the referral priority is downgraded on the basis of the result.

Primary care

We advise that:

- Patients with a positive FIT ($\geq 10\mu\text{g Hb/g}$) are notified of the result and referred to secondary care as a suspected cancer priority. Safety netting advice should be provided to contact the General Practice if communication is not received from secondary care within 2 weeks
- General practices have systems in place to identify and remind patients that have not returned a FIT sample within 2 weeks of request. Where no FIT result can be obtained, clinicians should use existing guidelines to assess the risk of colorectal cancer^{2,4}
- Patients with a negative FIT are provided with safety netting advice to seek further medical review if they have a persistent or change in symptoms or have ongoing concern (outline safety netting letter included in Appendix A)

Secondary care

- GP's are notified of all referrals downgraded from a suspected cancer priority, including the reason for priority change and recommendations for safety netting
- Patients should be advised of referral downgrades⁵ (outline letter included in Appendix B)
- ACPGBI/BSG recommend that patients should not be excluded from referral from primary care for symptoms based upon the basis of FIT testing alone. In cases where secondary care assessment or investigation is not deemed necessary following receipt of a referral, a clear plan of action should be described, including⁶:
 - i. Specific changes in symptoms to flag
 - ii. Re-referral thresholds
 - iii. Routes to assist in further management (e.g. local pathways)

Pathway Governance

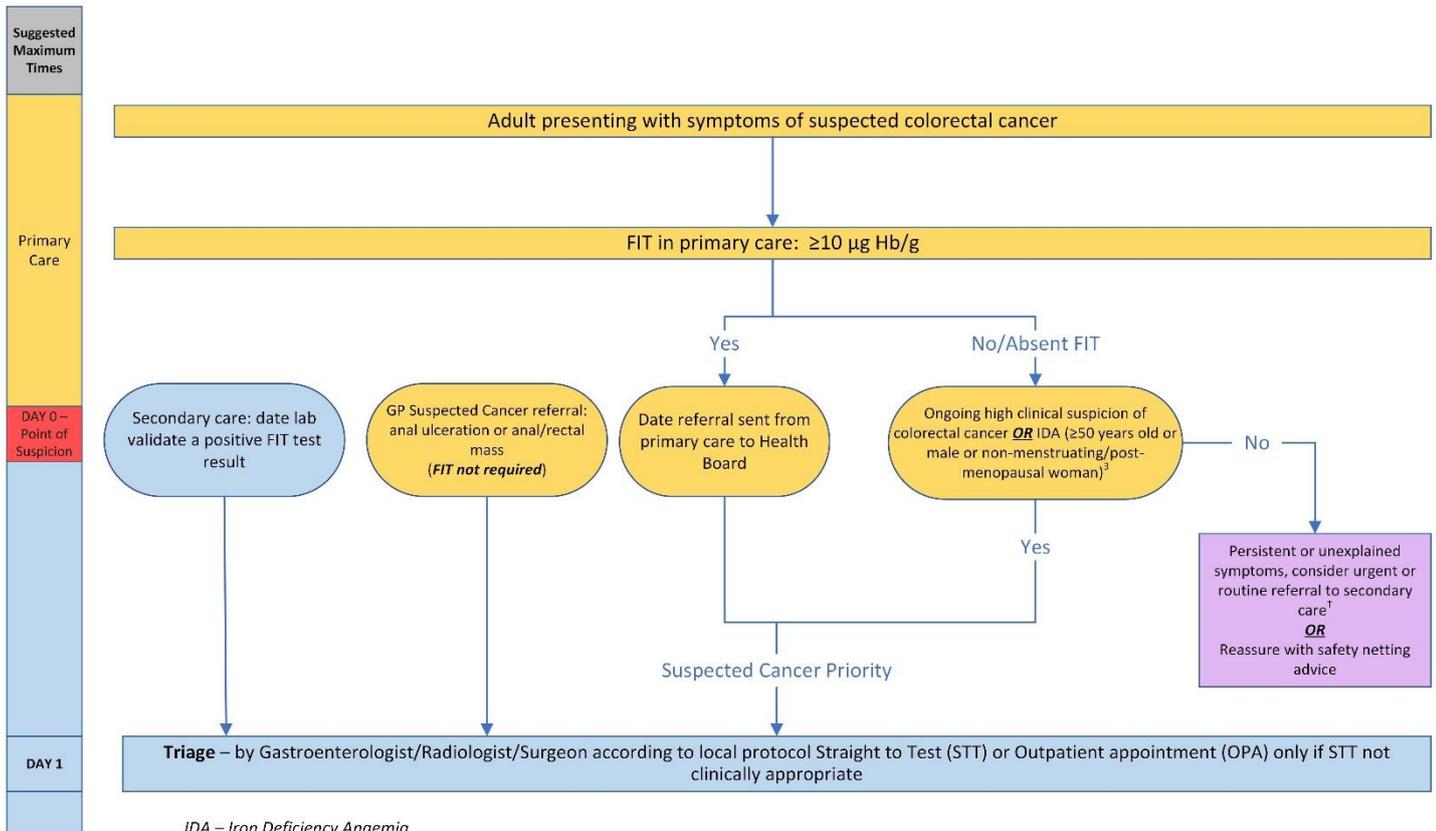
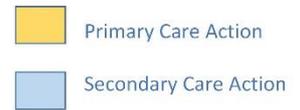
We recommend that Health Board colorectal MDT's document FIT negative cancer diagnoses and review the pathway of individual cases, including changes in referral priority, to identify any opportunities for learning or emerging themes

In the event of supply chain issues with FIT kits, we recommend that clinicians should use existing guidelines to assess the risk of colorectal cancer^{2,4}

Educational Material

Supportive educational material is available for professionals through [GatewayC](#). Patient information is available through CRUK ([FIT Symptomatic | Cancer Research UK](#))

Symptomatic FIT Pathway



IDA – Iron Deficiency Anaemia

[†] Advise management as per local pathways. BSG suggests referral of patients with persistent/recurrent anorectal bleeding for flexible sigmoidoscopy.

Patients with an abdominal mass suspicious of malignancy should have a FIT undertaken alongside investigation (e.g CT abdomen) or referral

¹ Monahan KJ et al. Faecal immunochemical testing (FIT) in patients with signs of symptoms of suspected colorectal cancer (CRC): a joint guideline from the Association of Coloproctology of Great Britain and Ireland (ACPGBI) and the British Society of Gastroenterology (BSG). Gut. Published Online First 12 July 2022

² NICE. Quantitative faecal immunochemical tests to guide referral for colorectal cancer in primary care. Diagnostics guidance [DG30]. 2017. Retrieved from: <http://www.nice.org.uk/guidance/DG30>

³ Snook J et al. British Society of Gastroenterology guidelines for the management of iron deficiency anaemia in adults. Gut 2021;70(11):2030-2051

⁴ NICE. Suspected cancer: recognition and referral. NICE guidance [NG12]. Updated 2021. Retrieved from: <http://www.nice.org.uk/guidance/ng12>

⁵ [Suspected cancer pathway: guidelines \(WHC/2023/025\) | GOV.WALES](#)

⁶ National Endoscopy Programme. National framework for the implementation of FIT in the symptomatic service. Updated 2021. Retrieved from: <https://collaborative.nhs.wales/programmes/endoscopy/workstreams1/clinical-pathways/>

BEST PRACTICE GUIDANCE

<p>Vetting & Triage</p>	<p>It is recommended that the triage of referrals is undertaken using an electronic system (e.g. Welsh Patient Referral Service) to improve the timeliness, traceability and governance of pathways.</p> <p>Referrals received as suspected cancer (USC) should be prioritised within 1 day and urgent / routine referrals within 3 days due to the potential need for upgrade to suspected cancer (pathway entry date: date referral originally made by primary care).</p>
<p>Direct booking diagnostics</p>	<p>It is recommended that patients attending a face-to-face outpatient clinic appointment as their first point of contact can 'direct book' any onward diagnostic tests such as endoscopy and CT scans on the same day (i.e., leave the hospital with an appointment date and any preparation required for the test).</p>
<p>Accelerated Imaging</p>	<p>It is recommended that following suspected malignant findings at endoscopy, patients should have a staging CT thorax, abdomen, and pelvis (CT TAP) on the same or next day, and for rectal cancers, an MRI scan within 3 days. These scans should be reported within 2 days.</p>
<p>Key worker role</p>	<p>It is recommended that key workers facilitate additional staging radiology (e.g. MRI liver, PET) and contact the pathology department to request NGS testing (stage IV tumours) if indicated following accelerated imaging to support MDT discussions.</p> <p>It is recommended that the key worker facilitates discussions with the relevant MDT members as timely as possible, without needing to wait until the next MDT meeting.</p>
<p>Physiological optimisation</p>	<p>It is recommended that if diagnostic investigations (endoscopy or 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.</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 resources such as nutritional support, smoking cessation advice, exercise prehabilitation and intravenous iron.</p>
<p>Abnormal straight to test radiology results</p>	<p>If colorectal cancer is suspected on straight to test radiology imaging, a process should be in place to refer the patient directly to colorectal or gastroenterology services.</p>
<p>Preservation of tissue for genomics</p>	<p>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.</p>

DEFINITIONS

Decision to Treat	<p>The DATE on which a Decision To Treat is made. For the cancer data sets, the DECISION TO TREAT 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: NHS Data Dictionary</p>
Direct to Test	<p>GPs have direct access to diagnostic endoscopy, ultrasound, MRI, X-ray and CT for people with suspected cancer.</p> <p>Source: National Institute for Health and Care Excellence, Quality Standard 2016 (QS 124)</p>
First Definitive Treatment	<p>First Definitive Treatment is the first CLINICAL INTERVENTION intended to manage a PATIENT's disease, condition or injury and avoid further CLINICAL INTERVENTIONS. What constitutes First Definitive Treatment is a matter of clinical judgement in consultation with others, where appropriate, including the PATIENT.</p> <p>Source: NHS Data Dictionary</p>
Next Generation Sequencing (NGS)	<p>The advent of next generation sequencing (NGS) technology has revolutionised the scale at which genetic testing can be performed, enabling the analysis of many more genes within the same assay. This allows multiple variants (mutations) to be detected per sample. Large gene panel tests (>500 genes) for cancer testing are rapidly being adopted in the UK.</p> <p>Source: Genome UK: the future of healthcare 2020</p> <p>AWMGS - Cymru Service for Genomic Oncology Diagnoses (CYSGODI) (medicalgenomicswales.co.uk)</p>
Safety Netting	<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: Royal College General Practitioners</p>
Straight to Test	<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.”</p> <p>Source: Delivering Cancer Waiting Times NHSE</p>
Teenagers and Young Adults (TYA) Service	<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: National Institute for Health and Care Excellence (NICE), 2014. Cancer services for children and young people (QS55)</p>

CLINICAL EVIDENCE

<p>Point of Suspicion/ Referral</p>	<p>The point of suspicion is when a clinician refers a patient or requests a test concerned that a patient may have cancer. Pathway start dates are defined in the following guidance:</p> <p>Single Suspected Cancer Pathway Definitions (December 2018)</p> <p>Additional information:</p> <p>Cancer Risk Assessment Tool (RAT)</p> <p>Q Cancer Risk Assessment Tool</p> <p>FIT in patients with signs or symptoms of suspected CRC: A joint guideline from ACPGBI and BSG</p>
<p>Diagnosis and Management</p>	<p>National Institute for Health and Care Excellence – NG151 guidance for colorectal cancer</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 to achieve the outcomes that matter to them’ (Cancer Quality Statement, 2021).

<p>Key Worker</p>	<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. National Institute for Health & Care Excellence (NICE, 2012) CG138 Clinical Guideline: Patient Experience in adult NHS services</p> <p>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”.</p> <ol style="list-style-type: none"> 1. All cancer patients must have an allocated key worker 2. Allocation / Review of key worker to take place at key time points including: <ol style="list-style-type: none"> a. Around the time of diagnosis *please note: allocation of key worker may 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. b. Commencement of treatment <p>Key workers for cancer patients (Welsh Health Circular /2014/001) GOV.WALES</p> <p>Cancer Improvement Plan for Wales</p>
<p>Meeting People’s Needs</p>	<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.</p> <p>National Institute for Health & Care Excellence (NICE, 2012) CG138 Clinical Guideline: Patient Experience in adult NHS services</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"> • Around diagnosis <i>*please note: undertaking a Holistic Needs Assessment may 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> • At commencement, during, and at the end of treatment. <p>National Institute for Clinical Excellence (NICE, 2004) CSG4 Improving Supportive & Palliative care for adults with cancer</p> <p>Ideally Holistic Needs Assessments should be undertaken electronically. Cancer Improvement Plan for Wales The Macmillan eHNA is <i>one</i> tool which is both valid and reliable. Snowden A & Fleming M (2015) Validation of the electronic HNA.</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>whssc.nhs.wales/commissioning/whssc-policies/fertility/specialist-fertility-services-commissioning-policy-cp38-feb-2020/</p>
<p>Health Optimisation / MECC</p>	<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>National Institute for Health & Care Excellence (NICE, 2012) CG138 Clinical Guideline: Patient Experience in adult NHS services</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>Welsh Government (2018) A Healthier Wales. Welsh Government (2015) Wellbeing of Future Generations Act.</p> <p>Making Every Contact Count (MECC), is a behaviour change approach that helps health and social care professionals to help people to improve their health and wellbeing through prevention and early intervention. phw.nhs.wales/about-us/board-and-executive-team/board-papers/board-meetings/2022-2023/30-march-2023/board-papers-30-march-2023/412a-board-20230330-strategic-plan-imtp-2023-2026/</p> <p><i>Lifestyle advice / resources are available from Making Every Contact Count (MECC)</i></p> <p><i>*Please note: Whilst addressing concurrent comorbidities and health risk behaviours is the responsibility of all health and social care professionals, at every contact throughout the pathway; earliest possible intervention may impact on cancer treatment choices / outcomes (especially in respect to tobacco smoking).</i> National Institute for Clinical Excellence (NICE, 2018) NG92 NICE Guideline Stop Smoking Interventions and services.</p>
<p>Prehabilitation</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>National Institute for Health & Care Excellence (NICE, 2012) CG138 Clinical Guideline: Patient Experience in adult NHS services</p>

	<p>Welsh Government (2018) A Healthier Wales.</p> <p>Welsh Government (2015) Wellbeing of Future Generations Act.</p> <p>The Quality Statement for Cancer.</p>
Rehabilitation	<p>All patients will have their needs for rehabilitation services assessed, with referral to an appropriate level of rehabilitative support, throughout the patient pathway.</p> <p><i>*Please note: not all patients will require specialist cancer rehabilitation services. Referral into non-cancer rehabilitation, self-management, and fitness services may be suitable to meet some patients' needs.</i></p> <p>National Institute for Health and Care Excellence (NICE) CSG4 (2004) resources for improving supportive and palliative care for adults with cancer.</p>
Patient Reported Outcome Measures (PROMs) / Patient Reported Experience Measures (PREMs)	<p>Patient Reported Outcome Measures (PROMs) are questionnaires that patients are asked to complete before and after treatment to assess the impact on health and wellbeing.</p> <p>Some of the Cancer Site Groups (CSGs) have been working with the International Collaboration for Health Outcome Measurement (ICHOM), Value Based Healthcare Team, National PROMS, PREMS, & Effectiveness Programme (NPP&EP) and other partners, to pilot tools and data capture methods, which will inform a consistent approach to PROMS & PREMS for cancer. The Quality Statement for Cancer</p> <p><i>*Please note: there are outstanding questions relating to tool selection, data capture intervals, data capture methods and data analysis / reporting which may prevent the implementation of PROMS & PREMS across all pathways at this time. PROMS & PREMS have 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 any time 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. Welsh Government (2018/19). Chief Medical Officer Annual Report</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>
Communication	<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</p>

	<p>minimum of delay. Referrers must ensure that the patient is aware and agrees for a suspected cancer referral to be made.</p> <p>Suspected cancer pathway: guidelines (WHC/2023/025) GOV.WALES</p> <p>Treatment Summary</p> <p>A treatment summary is a tool completed by secondary care professionals after a significant phase of a patient's cancer treatment. A treatment summary describes the patient's cancer diagnosis, prognosis, and aim, types and side effects of any treatment that they have had. It also highlights any signs and symptoms of recurrence that the patient needs to be aware of. It is designed to be shared with the person living with cancer and their GP either electronically or as a paper document, and should use easy to understand, clear and concise language. Additionally, it can be used by the person affected by cancer to help inform other health and social care professionals, employers/occupational health or financial institutions e.g. benefits services or banks, about their cancer care and treatment.</p> <p>Endoscopy</p> <p>Patient information for all relevant procedures is given to patients ahead of the procedure.</p> <p>There are a range of communication methods and materials to inform patients about what they should expect from the service (such as a website, written information, or specialised communication, e.g., pictures).</p> <p>Patients are informed if they are suspected of having a malignancy on the same day as the procedure unless considered to be in the patient's best interest not to do so. This should be documented.</p> <p>Patients and carers are told the outcome of the procedure and ongoing care, accompanied with a copy of the endoscopy report (or a patient-centred version).</p> <p>If a cancer is suspected, the patient is referred to a relevant cancer clinical nurse specialist (CNS) / key worker who offers contact with the patient before or soon after discharge from their diagnostic procedure.</p> <p>Endoscopy reports are completed on the day of the procedure and include follow-up details and are sent to the patient's GP and the referring clinician (if different) within 24 hours of the procedure.</p> <p>There is a process for referring patients with a suspected or definitive cancer diagnosis to the multidisciplinary team (MDT).</p> <p>Guidance - GRS standards UK 2023.pdf (thejag.org.uk)</p>
<p>Research</p>	<p>Patients should have the opportunity to take part in research and clinical trials where available.</p> <p>People in research Health Care Research Wales (healthandcareresearchwales.org)</p> <p>EC Trial Finder ECMC (ecmcnetwork.org.uk)</p>