



# NATIONAL OPTIMAL PATHWAY FOR TEENAGE AND YOUNG ADULT CANCER:

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## Point of Suspicion to First Definitive Treatment (aged 16 -24)

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<b>Owner: Teenage and Young Adult Cancer Site Group</b>

# FOREWORD

The NHS Wales National Optimal Pathways (NOPs) have been developed as part of the Single Cancer Pathway (SCP) programme of work. They aim to establish consistent generic and site specific pathways that describe all routes of entry onto the pathway 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 Teenage and Young Adult NOP is designed to help teenage and young adult cancer service providers and their commissioners see the basic structure of an effective and efficient teenage and young adult 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.

The Teenage and Young Adult NOP is a unique cross-cutting pathway to work alongside the site-specific NOP for patients aged 16-24. Site-specific NOPs must always be viewed in parallel with the teenage and young adult NOP for patients of this age-range. The teenage and young adult NOP is designed to ensure all young people have access to specialist age specific psychological, social, financial, educational and emotional support, as well as clinical expertise on teenage and young adult cancer and access to peer support. This is facilitated from the teenage and young adult multidisciplinary team. Referral to the teenage and young adult multidisciplinary team meeting is an essential standard of the Wales Teenage and Young Adult Cancer Standards (2012). The Teenage and Young Adult Multidisciplinary team work in collaboration with key 3<sup>rd</sup> sector organisations to deliver this support across Wales, including; Teenage Cancer Trust, Clic Sargent, Maggie's, Tenovus and Macmillan.

It is recognised that the introduction of the National Optimal Pathway for teenage and young adult Cancer may present challenges for the teenage and young adult multidisciplinary team. However, introducing a nationally agreed, clinically endorsed pathway will support service improvement. They 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 Consulted

The Teenage and Young Adult Cancer Site Group (CSG) is led by Dr. Clare Rowntree, Consultant Haematologist. 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 June 2019. An early draft was sent to the Teenage and Young Adult Multidisciplinary Team (MDT), Health Boards and Velindre NHS Trust in August 2019. Separate workshops were also held with the Clinical Nurse Specialist (CNS) and Allied Health Professional (AHP) members to embed the 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 December 2019 from NHS Wales's stakeholders, including National Imaging and Pathology Networks and the Third sector, 11 responses were received and these were all carefully considered during the revision process, prior to a final version being issued in January 2020.

**Dr Clare Rowntree** (Teenage and Young Adult CSG Lead Clinician)

**Bethan Ingram** (Teenage and Young Adult Lead Nurse)

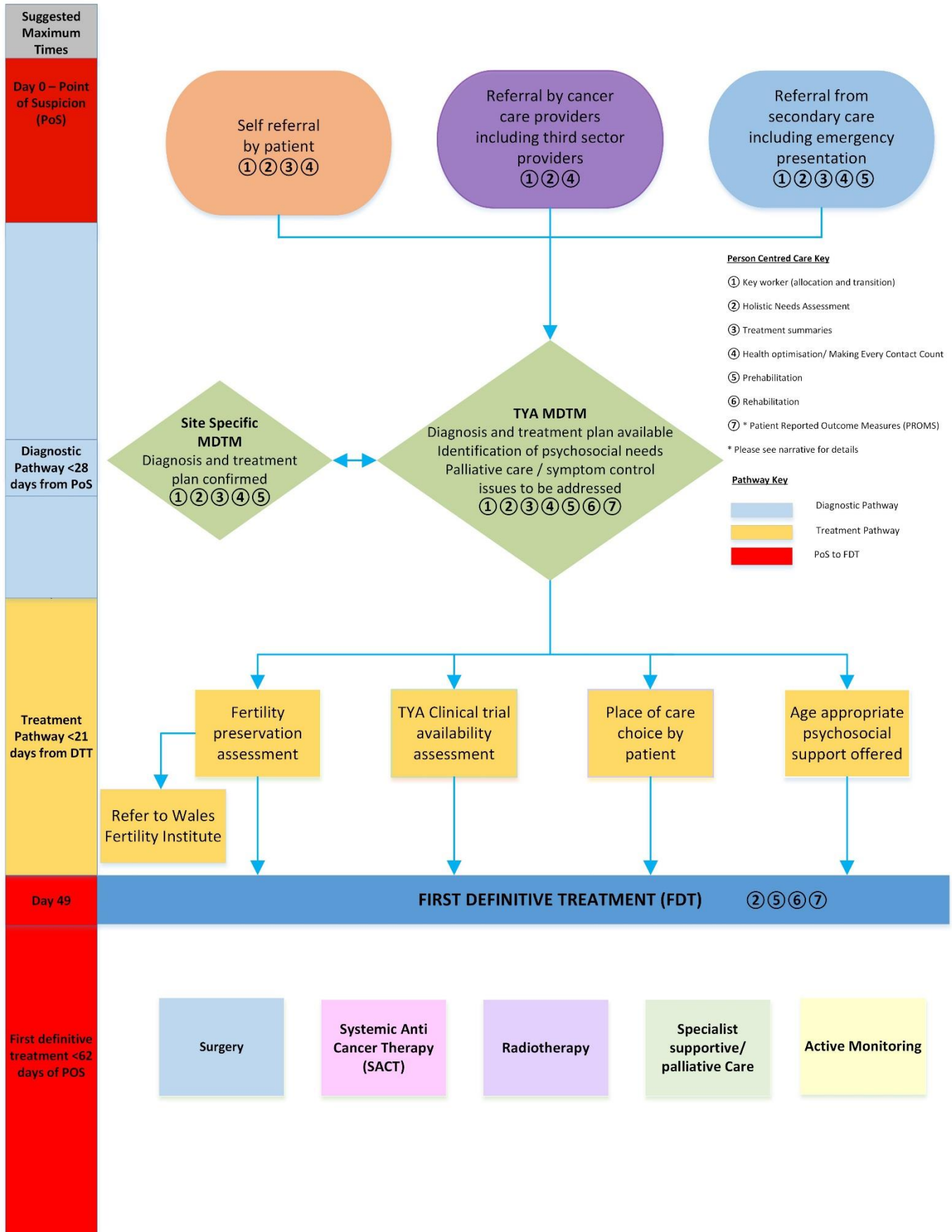
**Faye Blackborow** (Teenage and Young Adult Nurse Practitioner)

**Bethan Hawkes** (Macmillan Lead Cancer Nurse - Wales Cancer Network)

**Professor Tom Crosby** (National Cancer Clinical Director - Wales Cancer Network)

Date 11/02/20

## National Optimal Cancer Pathway for Teenagers and Young Adults with Cancer for patients aged 16-24 years from Point of Suspicion (POS) to First Definitive Treatment (FDT) – To be used in conjunction with a site specific pathway



# DEFINITIONS

<p><b>Straight to Test</b></p>	<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: <a href="#">Delivering Cancer Waiting Times NHSE</a></p>
<p><b>Direct to Test</b></p>	<p>GPs have direct access to diagnostic endoscopy, 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>
<p><b>Safety Netting</b></p>	<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>
<p><b>Decision to Treat</b></p>	<p>The DATE on which a <b>Decision to Treat</b> is made. For the cancer data sets, the <b>DECISION TO TREAT DATE</b> 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>
<p><b>First Definitive Treatment</b></p>	<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: NHS Data Dictionary</p>
<p><b>Teenagers and Young Adults (TYA)</b></p>	<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="#">Welsh Assembly Government, 2012. National Standards for Teenagers and Young Adults with Cancer Aged 16-24 (2012)</a>   <a href="#">National Institute for Health and Care Excellence (NICE), 2014. Cancer services for children and young people (QS55)</a></p>

# CLINICAL EVIDENCE

<p><b>Point of Suspicion/ Referral</b></p>	<p><a href="#">Single Suspected Cancer Pathway Definitions (December 2018)</a></p> <p><a href="#">National Institute for Health and Care Excellence (NICE) NG12 Suspected Cancer Referral Guidance</a></p> <p><a href="#">Cancer Risk Assessment Tool (RAT)</a></p> <p><a href="#">Q Cancer Risk Assessment Tool</a></p>
<p><b>Diagnosis and Management</b></p>	<p>Refer to cancer site specific NOP for diagnosis</p> <p><a href="#">Welsh Assembly Government, 2012. National Standards for Teenagers and Young Adults with Cancer Aged 16-24 (2012)</a></p>

# PERSON CENTRED CARE

<p><b>Key Worker</b></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. <a href="#">National Institute for Health &amp; Care Excellence (NICE, 2012) CG138 Clinical Guideline: Patient Experience in adult NHS services</a></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"> <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, endoscopy.</i></li> <li>b. Commencement of treatment</li> </ol> </li> <li>3. When not under active management by the cancer MDT, the Key worker could be a member of the primary care team. This involvement is critical as many patients living with cancer also live with 2 or more other chronic conditions.</li> </ol> <p><a href="#">Key workers for cancer patients (Welsh Health Circular /2014/001) GOV.WALES</a>  <a href="#">Welsh Government. Cancer Delivery Plan for Wales 2016-2020.</a></p> <ol style="list-style-type: none"> <li>4. The TYA MDT may assign a TYA key worker to work in conjunction with the site—specific key worker as required.</li> </ol>
<p><b>Holistic Needs Assessment and Associated Care Plan</b></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. <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;  <a href="#">National Institute for Clinical Excellence (NICE, 2004) CSG4 Improving Supportive &amp; Palliative care for adults with cancer</a>  Wales Cancer Network (2016). <a href="#">Guidance document to support implementation of Holistic Needs Assessment (HNA) and associated care plans for the person affected by cancer.</a></li> </ul> <p>Ideally Holistic Needs Assessments should be undertaken electronically. <a href="#">Welsh Government. Cancer Delivery Plan for Wales 2016-2020.</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).  <a href="#">Welsh Government (2018) A Healthier Wales.</a>  <a href="#">Welsh Government (2015) Wellbeing of Future Generations Act.</a></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. <a href="#">Public Health Wales Strategic Plan 2018-2021</a></p> <p><b><i>Lifestyle advice / resources are available from <a href="#">Making Every Contact Count (MECC)</a></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>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></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.</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 Standards for Rehabilitation of Adult Cancer Patients (2010) GOV WALES</a>  <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>

<p><b>Patient Reported Outcome Measures (PROMs) / Patient Reported Experience Measures (PREMs)</b></p>	<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><i>Some</i> 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="#">Welsh Government. Cancer Delivery Plan for Wales 2016-2020.</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 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>
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