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NATIONAL OPTIMAL PATHWAY FOR MULTIPLE MYELOMA:

1st EDITION (2025)

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

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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.

Multiple myeloma, or myeloma is the second most common blood cancer. The myeloma NOP is designed to help haematology cancer service providers and their commissioners see the basic structure of an effective and efficient myeloma cancer pathway. In essence, it 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 Myeloma may present challenges for the haematology multidisciplinary teams and NHS providers due to lack of resource. 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 CONSULTATION

The Haematology Cancer Site Group (CSG) is led by Dr. Jonathan Kell, Consultant Clinical Haematologist. A pathway subgroup was set up to develop the pathway. The development of the myeloma national optimal pathway has been led by Consultant Haematologists, Dr. Ceri Bygrave, Dr. Helen Jackson and Dr. Gemma Scott. Work on the pathway commenced in 2021.

The CSG includes representation from the full range of professions involved in delivering haematological cancer services. All were invited to contribute and comment on the development of the optimal pathway during a range of workshops, CSG meetings and educational days. 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) elements into the pathway, ensuring all patient's needs are assessed and met in a timely manner. Wider consultation feedback was gained in September 2025 across NHS Wales stakeholders, including primary care, National Imaging and Pathology Networks and the third sector. All responses were carefully considered and content amended accordingly.

Dr Ceri Bygrave (Pathway Lead Clinician)

Dr Vicki Ware (Consultant Haematologist)

Dr Gemma Scott (Consultant Haematologist)

Dr Jonathan Kell (CSG Lead Clinician)

Professor Tom Crosby (National Cancer Clinical Director for Wales)

MYELOMA TUMOUR PATHWAY

Myeloma is a malignant clonal plasma cell disorder where the abnormal clone of plasma cells secretes a specific type of immunoglobulin, called a paraprotein and or excess free light chains (kappa or lambda) in the majority of cases. Five percent of myeloma cases are non-secretory with no measurable disease markers in the peripheral blood. Paraproteins may be present for many years before true myeloma develops, these benign conditions are known as MGUS (monoclonal gammopathy of undetermined significance) and Smouldering or Asymptomatic Myeloma.

Symptoms of myeloma can be summarised as CRAB:

- C Hypercalcaemia
- R Renal failure (due to the disease process)
- A Anaemia (not due to any other cause)
- B Bone disease (due to osteolytic destruction of the skeleton)

Myeloma can also present with extramedullary and soft tissue plasmacytomas and there are some clinical biomarkers of High-risk Smouldering Myeloma where early treatment may be recommended (these are >60% plasma cells in the marrow, SFLC ratio > 100 or < 0.01 and >1 focal lesion > 5mm in diameter on whole body MRI).

A 'myeloma screen' should include:

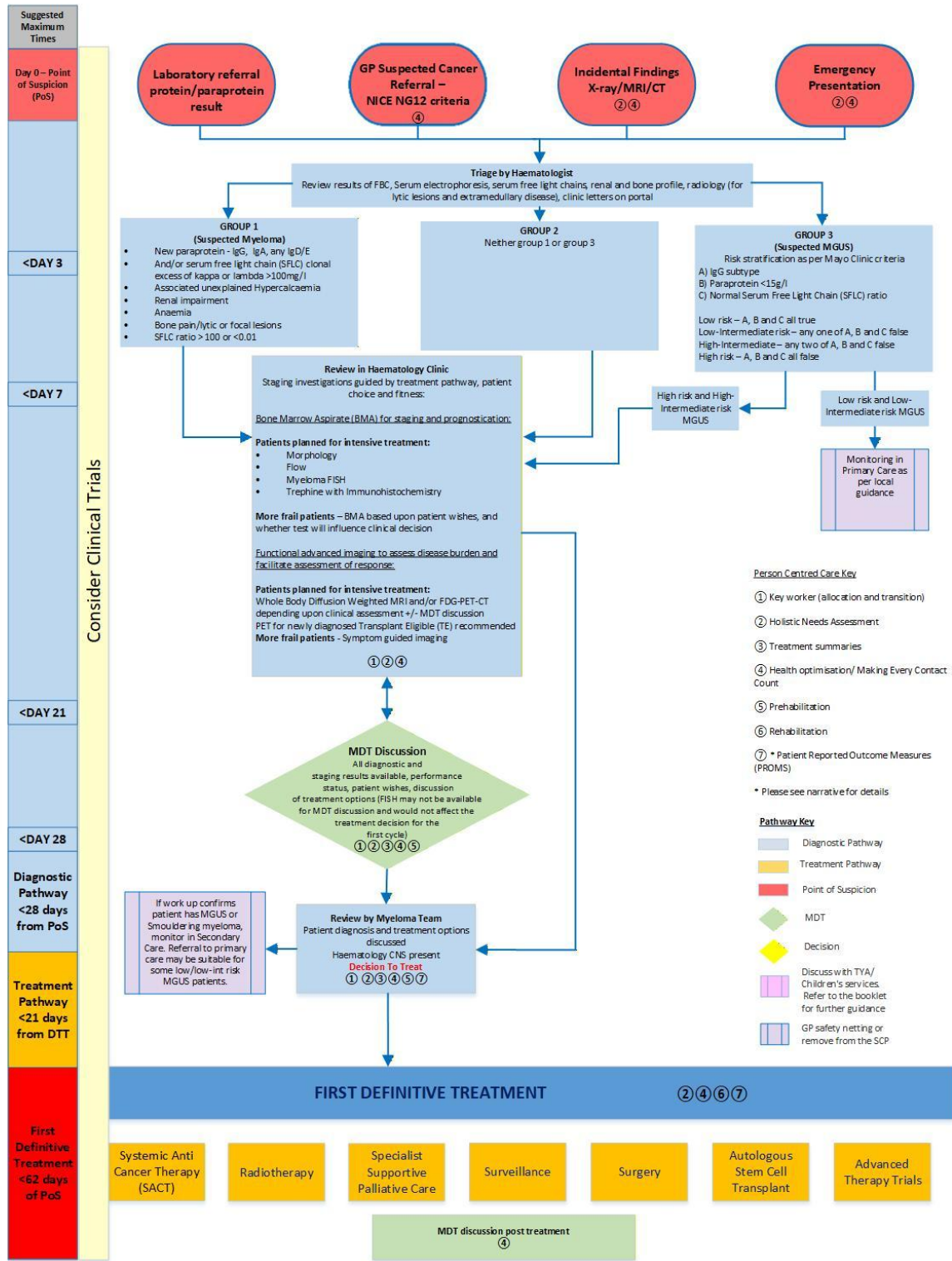
- Serum electrophoresis and immunoglobulin levels (myeloma is characterised by 'immunoparesis with suppression of at least 1 polyclonal immunoglobulin level IgG/IgA/IgM and a paraprotein). Non-secretory cases may show immunoparesis only.
- Serum free light chains
- Full blood count
- Renal, liver and bone profile

All these investigations are available to primary care, and a GP Myeloma test set is in development on Welsh Clinical Portal. Definitive diagnosis generally requires bone marrow biopsy, which is performed in secondary care.

Patients diagnosed with Myeloma in South Wales should be discussed in the appropriate local Haematology MDT, with complex cases requiring discussion in the Myeloma Regional MDT meeting hosted by the University Hospital of Wales (UHW), Cardiff. Patients diagnosed with Myeloma in North Wales should be discussed in the appropriate local Haematology MDT, with complex cases discussed in a Myeloma Regional MDT meeting hosted by The Christie Hospital, Manchester.



National Optimal Cancer Pathway for Suspected and Confirmed Multiple Myeloma: Point of Suspicion (PoS) to First Definitive Treatment (FDT) for patients 16 and over



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 ensure the timeliness, traceability and governance of pathways.</p> <p>Referrals received as urgent suspected cancer (USC) should be prioritised within 1 working day and urgent / routine referrals within 3 working days due to the potential need for upgrade to suspected cancer (pathway entry date: date referral originally made by primary care).</p>
<p>Accelerated Imaging</p>	<p>It is recommended that patients should have a whole body MRI and PET-CT scan. Delays to the scanning and reporting of the PET-CT will have an impact on the timeliness of treatment.</p> <p><u>British Society of Haematology and UK Myeloma Society, good practice paper (2024) Advanced imaging for earlier diagnosis and morbidity prevention in multiple myeloma</u></p>
<p>Key worker role</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. Due to the complex nature of this cancer, early contact with the MDT lead and nurse specialists is encouraged, in order to provide timely guidance.</p>
<p>Physiological optimisation</p>	<p>It is recommended that if patients are embarking on treatment for myeloma that teams give thought to patient fitness, optimisation to run concurrently with pathological staging investigation. This could include consideration of the need for respiratory, cardiology (e.g. echocardiogram) and endocrinology investigation. Prehabilitation including nutritional support, and smoking cessation advice (if not provided previously).</p>
<p>MyPOS – Patient Reported Outcome Measures (PROMS)</p>	<p>Patient Reported Outcome Measures (PROMs) for myeloma patients will be collected using the validated MyPOS questionnaire.</p> <p><u>Palliative care Outcome Scale (POS) - Home (pos-pal.org)</u></p> <p>Other Quality of Life Assessment Tools are also helpful to provide an understanding of patients’ health and holistic needs.</p> <p><u>EQ-5D-3L EuroQol</u></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 suspected of 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>Gene expression profiling (GEP) has been introduced as a tool for risk stratification in multiple myeloma based on the genetic make-up of myeloma cells. E.g. SKY92.</p> <p>Source: Gene Expression Profiling in Multiple Myeloma: Redefining the Paradigm of Risk-Adapted Treatment - PubMed (nih.gov)</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>

	Source: National Institute for Health and Care Excellence (NICE), 2014. Cancer services for children and young people (QS55)
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CLINICAL EVIDENCE

Point of Suspicion/ Referral	<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> <p>Single Suspected Cancer Pathway Definitions (December 2018)</p> <p>Additional information:</p> <p>Clinical Decision Support Tools: Cancer Research UK</p> <p>Q Cancer Risk Assessment Tool</p>
Diagnosis and Management	NICE Guidelines (NG35) Myeloma: diagnosis and management

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).

Key Worker	<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 <i>*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.</i> 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>
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<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><u>National Institute for Health & Care Excellence (NICE, 2012) CG138 Clinical Guideline: Patient Experience in adult NHS services</u></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><u>National Institute for Clinical Excellence (NICE, 2004) CSG4 Improving Supportive & Palliative care for adults with cancer</u></p> <p>Ideally Holistic Needs Assessments should be undertaken electronically. <u>Cancer Improvement Plan for Wales</u> The Macmillan eHNA is <i>one</i> tool which is both valid and reliable. <u>Snowden A & Fleming M (2015) Validation of the electronic HNA.</u></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><u>whssc.nhs.wales/commissioning/whssc-policies/fertility/specialist-fertility-services-commissioning-policy-cp38-feb-2020/</u></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><u>National Institute for Health & Care Excellence (NICE, 2012) CG138 Clinical Guideline: Patient Experience in adult NHS services</u></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><u>Welsh Government (2018) A Healthier Wales.</u></p> <p><u>Welsh Government (2015) Wellbeing of Future Generations Act.</u></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. <u>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/</u></p> <p><i>Lifestyle advice / resources are available from <u>Making Every Contact Count</u> (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</i></p>

	<p>(especially in respect to tobacco smoking). National Institute for Clinical Excellence (NICE, 2018) NG92 NICE Guideline Stop Smoking Interventions and services.</p>
Prehabilitation	<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>National Institute for Health & Care Excellence (NICE, 2012) CG138 Clinical Guideline: Patient Experience in adult NHS services Welsh Government (2018) A Healthier Wales. Welsh Government (2015) Wellbeing of Future Generations Act. 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, including timely access to allied health professional to meet individual holistic patient needs and goals.</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), National Value in Health Team, Home - Value in Health and other partners, to pilot tools and data capture methods, which will inform a consistent approach to PROMS 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 (2024/25) People's experience framework</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>

<p>Communication</p>	<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 agrees for a suspected cancer referral to be made.</p> <p><u>Suspected cancer pathway: guidelines (WHC/2023/025) GOV.WALES</u></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 patients 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>Research</p>	<p>Patients should have the opportunity to take part in research and clinical trials where available.</p> <p><u>People in research Health Care Research Wales (healthandcareresearchwales.org)</u></p> <p><u>EC Trial Finder ECMC (ecmcnetwork.org.uk)</u></p>