

# Guidelines for Managing Patients on the Suspected Cancer Pathway

December 2020

Version 2.0

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## Overview

### Document Summary

This document provides guidelines relating to the management of patients on a suspected cancer pathway and the reporting of performance against the cancer target. Any queries relating to the management and reporting of cancer waiting times should be sent to the [singlecancerpathway@wales.nhs.uk](mailto:singlecancerpathway@wales.nhs.uk). Operational issues will be will be addressed at the Cancer Operational Managers Group. Any queries that require a clinical input will be submitted to the relevant Clinical Reference Groups via the Wales Cancer Network. The Wales Cancer Network will maintain a log of queries and responses. This guidance will be reviewed at least annually.

This guidance has been written based on the following principles.

- The thresholds have been agreed to allow for patients who choose to delay their pathway, pathway delays for clinical reasons or pathways which are clinically complex.
- Patients need to have confidence that any advice or decisions affecting their treatment are based solely on clinical grounds, rather than the need to meet these standards.

This updated guidance (December 2020):

- Introduces new rules around the management of patients on a suspected cancer pathway
- Sets out the targets for the suspected cancer pathway
- Removes all adjustments and suspensions from a patient pathway
- Allows a patients pathway to be closed and a new one started after a period of medical or social unavailability of two months or more
- Introduces guidance around the treatment of subsequent skin cancers
- Includes the reporting of patients treated outside of NHS Wales when referred from secondary care in NHS Wales

## **Cancer Waiting Times Target**

1. The cancer waiting times (CWT) targets, were first introduced as part of the Service and Financial Framework targets in 2004/05. This document supercedes all previous guidance. This document is a working document recording the current position of CWT reporting and as such is subject to change over time.
2. From December 2020, a major change to the management of suspected cancer patients was introduced. The Suspected Cancer Pathway (SCP) following a period of dual reporting from June 2019, replaces the previous two standards – the Urgent Suspected Cancer and the non-Urgent Suspected Cancer. Further SCP guidance can be found here:

[Wales Cancer Network | SCP Key Documents](#)

3. The achievement of the cancer target is the responsibility of NHS Wales. The underlying principle of the cancer pathway is that patients should receive excellent care without delay.
4. Within the pathway waiting time, both the patient and the NHS in Wales have roles and responsibilities that are required to achieve this.
5. This document aims to clearly set out the rules to ensure that each patient's pathway waiting time begins and ends fairly and consistently regardless of where they were referred or treated. For the cancer pathway the clock continues when a patient moves across health boards/trust and/or consultants for the management and recording of their pathway.

## Cancer Waiting Time Target Definitions

6. The **waiting time for patients on the Suspected Cancer Pathway (SCP)** starts at the point at which cancer is suspected (See [Point of Suspicion \(POS\)<sup>1</sup> guidelines](#)) and ends at the start of first definitive treatment. The majority of all patients presenting with a suspicion of cancer should start treatment within 62 days from the point of suspicion (POS).
7. The performance target for the SCP from December 2020 is that at least 75% of patients start their first definitive treatment within 62 days of the point of suspicion.

## Guiding Principles

8. This guidance is to ensure that the patients' wait for suspected cancer diagnosis and treatment are measured and reported in a consistent and fair manner. The guiding principles of the CWT clearly reflect the prudent health principles. Patients should be managed with the aim of starting treatment at the earliest clinically appropriate time rather than against any performance measure.
9. There are a number of key principles which underpin the waiting times rules, and apply to the cancer target. These principles apply to all interactions with patients, and must be considered in the formation of all waiting times and access policies and procedures.

### **Do only what is needed and do no harm**

10. All patients should wait the shortest possible time for diagnosis and treatment.

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<sup>1</sup> See Annex 1

### **Care for those with the greatest health need first**

11. Clinical need should dictate the appropriate waiting time for any cancer pathway. The national cancer compliance target should not distort clinical urgency.

### **Public and professionals are equal partners through co-production**

12. The concept of a NHS/patient 'contract' around the delivery of waiting times is implicit and reflected in the definitions below. Both parties have rights and responsibilities within the arrangement. Health boards will be required to deliver high quality care within the target time, and to allow for patient choices within that time. Patients will be expected to make themselves available for treatment within reasonable timescales and at sites and times where the service is delivered, sometimes outside of the health board area. Their inability to do so may result in a longer waiting time.
13. It is important that the rights and responsibilities of the patient are explained to them at the time of referral, directly and supported through written resources. They should be signposted to appropriate electronic resources by health boards (including websites). This requires commitment from referrers and the need to ensure the availability of appropriate information resources for patients and healthcare staff. Patients have a duty to notify the NHS, hospital and GP of any changes in circumstances while they are waiting to be seen at any stage.
14. The information given to the public, must contain adequate information on the expected timescales, the anticipated process and their responsibilities to assist the NHS to provide efficient and effective treatment of their condition. Patients should be empowered through this information to question and monitor their own progress through their pathway journey. Patients should be encouraged to

become involved in all decisions relating to their care. This should include potential treatment options and administrative arrangements.

15. All appointments within a cancer pathway must be arranged under the rules relating to reasonable offer, and therefore be mutually agreed between the patient and the organisation. When a patient is removed from a pathway for reasons other than treatment, both the patient and referrer must be fully informed of the reasons behind this decision and any requirements for re-instatement.

**Reduce inappropriate variation through evidenced based approaches.**

16. All patient management methodologies should be transparent and guided by the principle that patients should wait the shortest time possible for treatment. This national guidance needs to be supported by local access policies for each health board.

**Scope of the targets**

17. The targets and reporting relate to all patients referred and treated in NHS Wales. The cancer pathway covers patients who are referred by a healthcare professional to a healthcare professional in secondary or tertiary care, including consultants who work in the community, and consultant to consultant referrals.
18. Those patients who are referred from NHS Wales secondary care to have their further investigation, and/or first definitive treatment undertaken outside of NHS Wales must be included in cancer waiting times reporting but those referred directly from primary care will not.
19. Those patients who are referred direct to secondary care outside of NHS Wales with suspected cancer for further consultation, further investigation, and/or first definitive treatment are not included in cancer waiting times unless they are treated in Wales.
20. All patients under 16 years at date of referral should be grouped as children's cancer; all others are grouped as adults.

21. In the case where a patient is initially seen by the specialist privately, but is then referred into NHS Wales for further consultation, further investigation, and/or first definitive treatment, the patient should be included under the SCP pathway reporting, at the point of that referral to the NHS. The point of suspicion is therefore the date of referral into the NHS.
22. In the case where a patient is initially seen under the NHS but chooses to have diagnostics privately and then return to the NHS for treatment, the Health Board must communicate with the patient that their pathway will be closed from the date the patient informs the Health Board they wish to have diagnostics privately and a new pathway opened when they then inform the health board they are ready to restart their NHS pathway.
23. The CWT applies to patients with a newly diagnosed cancer. Some patients may have metastases at first presentation and so the treatment may be to the metastatic site rather than the primary site.
24. When a patient is diagnosed with a second new cancer, which is not a recurrence, then the cancer targets will apply to the treatment of this second cancer as a new primary cancer. This includes Squamous Cell Carcinoma cancers<sup>2</sup>.
25. Treatment for recurrence of cancer i.e. a recurrence of the original primary cancer at a secondary site is excluded from the CWT targets. These will still be recorded in NHS Wales systems.

### **Clinical responsibilities**

The responsibilities of clinical staff in monitoring cancer waiting times

26. Waiting times for patients are one of the indicators of quality of service. Clinicians should make themselves aware of the current

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<sup>2</sup> Previously only the first instance of SCC would be included in cancer waiting times reporting. Now all instances of SCC primaries should be included.



waiting times applying to their service, and work with health boards to instigate action when those waiting times are not meeting the expected level of quality of care.

27. All healthcare professionals must be aware of national requirements and organisational policies in respect of waiting times. As part of this awareness, they should be actively aware of their own current waiting times and use this to discuss options and potential waits for their patients along their pathway.
28. Clinicians should ensure that their actions promote the principle of patients waiting the shortest possible clinically appropriate time for treatment.
29. Clinicians should also ensure that patients are fit to proceed with the most appropriate treatment. If they are not fit this should be discussed with the patient to understand their options.
30. Clinicians should make decisions in a timely manner, and ensure that any onward referrals are 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.
31. Clinicians must cooperate with agreed local systems to enable the recording of the clinical outcome of all interactions with patients, whether face-to-face or by video, phone or letter.
32. 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 for diagnosis.

33. 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.

### **Pathway Start**

34. The suspected cancer pathway begins at the point of suspicion of cancer (see Point of Suspicion (POS)<sup>3</sup> guidelines).

### **Referrals**

35. When the referral from primary care (including optometry and dentistry) to a consultant or any other healthcare professional where referral protocol exists, is received into secondary care, the pathway will start on the date the referral is made.
36. The referrer needs to communicate to the patient that they are being referred as urgent, potentially with suspected cancer (as per national guidance), and inform them that they should be contacted quickly by the hospital usually by phone. As such the contact details need to be validated and included in the referral.
37. When two cancers are concurrently referred into secondary care, they both remain on the SCP pathway as two separate cancer pathways.
38. When a patient is referred on suspicion of one cancer but during that period of care is diagnosed with another cancer (i.e. incidental finding) of greater clinical priority. The one with clinical priority will be treated first, but both pathways remain open.

An example of this would be if a patient was referred in with suspected colorectal cancer and while on this pathway is then admitted via accident and emergency department with haemoptysis

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<sup>3</sup> See Annex1

and is diagnosed with lung cancer. The lung cancer is determined by the teams as the clinical priority therefore this pathway will continue to treatment first. The colorectal pathway may be closed while the patient receives treatment for the lung cancer if this means that the patient is unavailable for a period of 2 or more months and a new colorectal pathway started when the patient is available again.

39. If a patient is referred as a 'suspected cancer' via rapid access referral route however, referral is downgraded at vetting or outpatient appointment, then following investigation such as biopsy, within 26-week time frame is found to be cancer, the original date of referral is the point of suspicion.
40. If a patient is started on a SCP within one tumour site group however, following investigation results indicate the diagnosis<sup>4</sup> falls under a different tumour site group, the 'point of suspicion' date should remain unchanged from the original date initially captured.
41. Referrers must use the most efficient and patient-centred approach to referral that reduces the steps needed to reach treatment, based on prudent healthcare principles. As part of the referral information, referrers should include verified up-to-date patient contact details including mobile phone numbers and email addresses where available. Referrers should seek the consent of the patient to be contacted by the health board by such means as text, email, video or telephone and indicate if consent is given for this, and this should be included within the referral information. Health boards must ensure that patients are seen by the most appropriate individual once the referral has been received and accepted.
42. Health boards should provide up-to-date information to referrers relating to the patient pathway that will be followed, the likely waiting time and the locations the service will be delivered from, in order that

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<sup>4</sup> So long as the original symptoms relate to the diagnosis and are not an incidental finding which would start a new pathway (see example in Appendix 2).

this can be communicated clearly to the patient. Discussions should also be supported by written information for patients either provided during consultation or by signposting where they can get additional information. Health boards should have systems in place to keep this information up-to-date and available to referrers.

43. When a referral is made to a clinician or specialty which does not treat this condition, but is treated by another clinician or speciality within the health board, the health board has the responsibility to direct the referral to the correct clinician / clinical team and the pathway does not stop.
44. When the health board directs a referral in error to a clinician who does not treat this condition, an onward referral to the appropriate clinician will not stop the pathway. The patient must be seen by the new consultant within the same CWT pathway.
45. If the referral has insufficient information to enable a clinical decision to be made, it should be returned to the referrer for completion with guidance on what is required. The CWT pathway will continue whilst the information is obtained as the delay is not related to a patient's breach of the shared contract, but due to NHS process.
46. Health boards need to work with primary care to ensure good quality information flows between the two areas to support effective patient care.
47. When the patient care transfers between organisations and or consultants, it is the responsibility of the transferring organisation to provide the correct pathway start date (PSD). The onward referral of patients should be standardised with the requirement that the PSD is provided by the referring consultant on the referral.
48. The receiving organisation must ensure that the clinically communicated PSD is correctly used and captured in its patient

admission system (PAS). This will ensure the ongoing wait is correctly continued across the pathway.

49. A referral is designated as a suspected cancer pathway when a suspicion of cancer is stated by the referrer and confirmed by the specialist initially receiving the referral. The SCP pathway start is defined in the POS document<sup>5</sup>.
50. A cancer pathway referral should be made quickly and safely, e-referral being the preferred method. The cancer targets will still apply to a referral received via another route.
51. A referral which has not been made as a suspected cancer pathway e.g. routine referral, may be subsequently upgraded to a suspected cancer pathway by the receiving specialist when he or she has viewed the referral information. The pathway start date is defined in the POS document.
52. If new information is presented and/or primary care request an upgrade of a routine referral to a suspected cancer pathway due to new symptoms, the 62 days commence from the date the upgrade is requested.
53. A referral may be downgraded by the specialist when he or she has viewed the referral information. The 26 week RTT target will apply from the point the referral was received in secondary care. This decision and reasons for any downgrade should be communicated to the referrer.

### **Booking processes**

54. The focus of the booking interaction should be on offering the first available date(s), in response to the clinical urgency of the pathway. Patient's needs should always be considered as much as possible.

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<sup>5</sup> See annex 1

55. Patients should be offered appointments at any location providing the required service, preferably at a venue that is nearest to their home. Venues that are some distance from the patient's home will be considered reasonable if this was explained to the patient when they were referred.
56. All dates offered must be recorded and available for subsequent audit. If the required information is not recorded, it will be considered that no reasonable offer has occurred.
57. All patient appointments should be booked using a patient-focused booking approach. The booking processes used by health boards need to be clearly communicated to patients at referral to ensure patients are clear on their role in agreeing dates in keeping with the principles of co-production. This must be adhered to, even when the organisation does not hold complete contact details for the patient.
58. Where a fully automated model is utilised and the health board contacts the patient offering a date the health board should have a process in place to allow the patient to play an active role in changing the appointment if it is not mutually agreeable. Whenever possible, organisations should ensure that patients are treated in turn, allowing for considerations of clinical priority (see section on direct booking).
59. Each attempt to contact the patient under the booking processes must be recorded and made available for subsequent audit.

#### Direct booking

60. Direct booking can take place in two ways. An appointment/test can either be booked in a face-to-face or virtual interaction with the patient or through a direct dialogue with the patient, phone/email and or text.
61. Under the direct booking process, if the appointment is being made by telephone the health board should make at least two attempts to contact the patient. These telephone calls must take place on

different days, and at least one must be outside normal working hours (Monday - Friday 9-5pm). If contact is not made with the patient then the health board should follow up with an alternative method of contact such as e-mail, text or in writing.

### **Inability to contact a patient**

62. It is important that health boards make it clear to patients their responsibility to make themselves reasonably available for treatment and in the interest of co-production that their contact details are correct/up-to-date. Where a health board is unable to contact a patient it is only appropriate to remove that patient from the waiting list following significant effort to contact them. All attempts to contact the patient should be recorded for audit purposes.
63. Significant effort involves at least two attempts to contact via phone on different days, at least one attempt must be outside of normal working hours (Mon-Fri 9-5). Written contact should also be sought where there is no response from the two telephone contacts. This should be followed up by a final reminder letter to the patient and referrer outlining the need and urgency for the patient to make contact with the health board and the consequences of not responding, as in removal from the waiting list.
64. If the patient has not responded to the attempted initial contact within two weeks, a letter should then be sent to the patient and referrer outlining that the patient is at risk of being removed from the pathway and clarity is needed as to whether the appointment/test is still required. If within two weeks from this, no contact is made by patient or referrer, then the patient can be removed.
65. If a patient subsequently makes contact with the health board following removal from the waiting list they will be restarted on the CWT target with a new pathway, with the new pathway starting on

the date contact is made. This should be communicated with the patient and referrer for clarity on CWT targets.

### **Refusal of a reasonable offer**

66. If the patient declares themselves as unavailable for the time period in which the offers are being made, and this is over 2 consecutive months, then they should be informed their pathway will stop and a new pathway started when they declare themselves available.

### **Could not attend (CNA)**

67. It is the health board's responsibility to communicate to the patient the need for and the urgency of their appointment as well as explaining the responsibility of the patient to make themselves available.
68. A CNA occurs when the patient gives prior notice of their inability to attend an appointment. A patient may give notice up to and including the day but prior to the actual time of the appointment.
69. Patients who have not kept an appointment at any stage along the pathway and have not notified the organisation in advance are identified as 'did not attend' (DNA).
70. If a patient CNA's within any stage of the pathway, a new appointment must be made as near to the date the patient states they are next available.
71. If a patient makes themselves unavailable for a period of 2 consecutive months or more they will be removed from the pathway and informed their pathway will be stopped and a new pathway started when they re-contact the health board to resume.



## **Did not attend (DNA)**

72. If the patient does not attend an appointment without giving notice, the patient should be contacted to re-arrange the appointment.
73. If the patient DNA's for the same appointment on two occasions, the clinician must decide whether to discharge the patient back to primary care or attempt to re-engage by communicating to the patient the need for and the urgency of their appointment, as well as explaining the responsibility of the patient to make themselves available. If discharged back to primary care the roles and responsibilities of the patient must be made explicit before re-referring into secondary care.

## **Attendance outcomes**

*(Example scenarios are available in appendix 2)*

74. An outcome must be recorded within the information system for every decision point in the pathway, whether the patient is present or not.
75. The defined outcome will fall into three categories: clock start, continue or stop.
76. Health boards need to ensure 100% compliance with outcome coding after any patient interaction, either face-to-face or virtual, to reduce the need for validation of activity.
77. CWT pathways are reported based on closed completed pathways, and no adjustments (see below) are to be made to the patient pathway.

## **Pathway continue outcomes**

78. A pathway continued outcome is used to define decision points along the pathway where the current pathway status will continue. Within a

CWT pathway, the pathway continues until a clinical decision to stop is reached. This may be that the patient is found not to have cancer, the treatment begins, the patient refuses treatment or dies.

79. If an appointment is cancelled by the organisation, the pathway will continue, and a new appointment must be booked as soon as possible.
80. All referrals within a cancer pathway to diagnostic tests, therapy services or anaesthetic assessment will continue the pathway.
81. When a patient is referred from an NHS organisation to an independent sector organisation as part of their NHS pathway, the pathway will continue.
82. Where responsibility for a patient's care is transferred between consultants for the same condition, the pathway will continue.
83. Where a patient's care takes place across more than one organisation the cancer pathway continues, whether the responsibility for care is transferred to a new consultant or not.

### **Pathway Stop**

84. If a patient is unavailable (for medical or social reasons) to move on to the next stage of the pathway for a period of 2 consecutive months or more, the pathway will be stopped. When the patient is available and ready to resume diagnostics/treatments a new pathway will start on the date the patient makes contact with the health board.
85. When the pathway is stopped due to medical reasons, health boards must have in place robust mechanisms to document the reason for the pathway closure. A plan must be in place with the aim that as soon as the patient is declared medically fit they are able to start a new pathway.

Examples where patients may be medically unavailable to proceed for a period of 2 consecutive months or more includes cardiac event or pulmonary embolism. It is a clinical decision whether the patient is medically available or not.

### **First Definitive Treatment (FDT)**

86. FDT is defined as the start of the initial intervention (treatment) aimed at removing or eradicating the patient's cancer completely or reducing tumour bulk and stabilising their symptoms. FDT stops the suspected cancer pathway.
87. If FDT is surgery, the pathway will stop after the surgical procedure has taken place, whether done on an inpatient or day case basis.
88. If FDT is chemotherapy and / or anti-cancer treatment, including hormone / endocrine / immunotherapy, the pathway will stop on the date that the first dose of the drug is administered to the patient, or the date on which the prescription of the drug is dispensed to the patient if self-administered.
89. If FDT is radiotherapy, the pathway will stop on the date that the first fraction of radiotherapy for this prescription is administered to the patient.
90. If FDT is specialist palliative care, the pathway will stop on the date of the first treatment/support meeting.
91. A purely diagnostic procedure, including biopsies, does not count as treatment unless the tumour is effectively removed by the procedure. If an excision biopsy is therapeutic in intent, that is, the intention is to remove the tumour, then this will count as FDT, irrespective of whether the margins were clear.
92. First treatment refers to the FDT and may not necessarily be the first planned treatment decided upon by the multi-disciplinary team.

93. It has been clinically agreed that for cancer pathways it is the start of treatment on a clinical trial that is the FDT point, not the agreement of the patient to join a trial. This should be closely reviewed by health boards to ensure that delay due to trials is not a factor.

### **New pathway start**

94. If a new referral from primary care is made for a patient or the discovery of a new primary cancer while on a cancer pathway, then a new pathway would start but only where this is found to be a new primary cancer as opposed to secondary or a recurrence.
95. If a patient is not diagnosed with cancer following initial investigation, but is placed on a watch and wait list and on review is discovered to now require treatment, a new pathway will be started. See watch and wait example in appendix 2.

Please note, this is not the same as active surveillance<sup>6</sup>. Active surveillance is for patients who have a cancer diagnosis confirmed.

### **Communicating the diagnosis to a patient**

96. All diagnoses of cancers should be made through direct (either face-to-face, by phone or video) communication with the patient, unless otherwise explicitly agreed with the patient.
97. Reasonable forms of communication with patients to confirm cancer has been ruled out include:
- direct communication with the patient, over phone, video or similar;

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<sup>6</sup> Active Surveillance: A treatment plan that involves closely watching a patient's condition but not giving any treatment unless there are changes in test results that show the condition is getting worse. Active surveillance may be used to avoid or delay the need for treatments such as radiation therapy or surgery, which can cause side effects or other problems. During active surveillance, certain exams and tests are done on a regular schedule. It may be used in the treatment of certain types of cancer, such as prostate cancer, urethral cancer, and intraocular (eye) melanoma. It is a type of expectant management.

- written communication by letter, or by email;
- face-to-face communication at an outpatient appointment.

98. Where direct communication is not possible due to the patient not having the mental capacity to understand a diagnosis, either temporarily or permanently, communication to the patient's recognised carer or a parent/guardian should be recorded in the same way as if the patient was told directly.

Examples where this could apply are: -

- Potentially patients with advanced dementia
- Patient who is unconscious
- A child where they are too young to understand the diagnosis.

This would not be appropriate where it is not possible to contact a patient.

99. Providers should ensure that communication is easy to understand, and that support is available to patients who would like further information. Providers should undertake audits of their communication practice to ensure that letters/emails are being received and understood by patients. An accurate record of all communication as confirmed by the patient must be maintained in the patient record.

## **Recording and reporting**

### **Reporting formats**

100. All waiting times must be reported according to the requirements of the [NHS Wales Data Dictionary](#). Organisations must consult the data dictionary for details of required formats, fields, timescales and routes of reporting.

101. Health boards must ensure that appropriate systems are in place to capture the information necessary to meet the requirements for reporting.
102. All patients who are not treated within the target should have an internal breach report completed detailing their pathway journey and outlining the lessons learnt and remedial actions taken within the health board. All patients who have waited too long from POS for their treatment and are suspected of coming to harm should have a clinical review undertaken and submitted to Welsh Government.

### **Accountability for monitoring and reporting CWT**

103. The health board receiving and accepting the patient's initial referral or request for test is responsible for reporting the patient's CWT. For example, Powys residents will all be referred to another health board, it is the receiving health board that will report that wait. If a Cardiff resident is referred to Cwm Taf Morgannwg (CTM) for suspicion and CTM accept that referral, then CTM will be responsible for reporting. However, if a CTM patient is referred and accepted by CTM for suspected cancer, but their treatment takes place in Cardiff, then the responsibility for reporting remains with CTM. The health board that accepts the initial referral is responsible for reporting the completed pathway.
104. All health boards involved in the diagnosis and treatment of the patient are responsible for monitoring the patient's pathway and making the data available to the reporting health board.
105. When the patient's cancer pathway involves more than one organisation or information system, health boards must ensure that appropriate information is communicated and shared in a timely fashion and CWT pathways are measured accurately, particularly when the pathway continues from referral through to investigation

and treatment, (e.g. when a specific tumour such as pancreatic or sarcoma is managed by a regional service).

106. When NHS activity is commissioned from an independent sector provider (non NHS), the health board commissioning the pathway is accountable for the monitoring and reporting of that patient's pathway. Health boards must ensure that communication protocols are utilised so that appropriate information is shared, and the CWT's are measured accurately.
107. When a referral is made to an English NHS provider, the English NHS provider is accountable for the monitoring of that patient's pathway. English NHS providers must ensure that communication protocols are utilised so that appropriate information is shared, and CWT's are measured accurately. The Welsh targets need to be communicated as part of any contracts with other NHS providers. It is the responsibility of the commissioning Welsh health board to ensure they have processes in place to monitor and performance manage their contracts for cancer provision, ensuring targets are met. All patients referred for treatment outside NHS Wales from secondary care will be included in CWT reporting.

### **Accountability for performance**

108. When the patient's CWT is managed entirely within a single health board, the accountability for performance against the targets lies with that health board.
109. When the patient's CWT involves more than one health board, the health board that received the patient's initial referral is accountable for performance against the CWT targets.
110. When NHS activity is commissioned from an independent sector provider or trust, the accountability lies with the health board commissioning the activity to monitor the patient's waiting times. The commissioning health board will need to ensure data is shared with

the reporting health board, if different, as the reporting of the patient's pathway remains with the health board who received the original patient referral.

111. Where NHS activity is commissioned from outside NHS Wales, the accountability for managing the patient's wait lies with the health board commissioning the activity. The commissioning health board will need to ensure data is shared with the reporting health board, if different, as the reporting of the patient's pathway remains with the health board who received the original patient referral.
112. Those patients who are referred direct to secondary care outside of NHS Wales with suspected cancer for further consultation, further investigation, and/or first definitive treatment are not included in cancer waiting times unless they are treated in Wales.
113. Where the patient pathway is commissioned by Welsh Health Specialised Services Committee (WHSSC), the accountability for performance against the targets lies with the health boards on whose behalf WHSSC is commissioning.



Appendix 1:

## Suspected Cancer Pathway Definitions – pathway start date

Version	9.0
Date	1 December 2020

## **Purpose of the Document**

This document outlines the requirements for identifying the pathway start date when measuring CWT on a Suspected Cancer Pathway (SCP). This supersedes all previous versions.

**The Suspected Cancer Pathway (SCP):** The SCP will measure CWT from the point of suspicion of cancer. This will ensure that all patients are treated as soon as safely possible from when first suspected of cancer. No patients should wait longer than 62 days. It is fundamental that the patient remains at the centre of the pathway, and the pathway system is in the interests of each patient.

The SCP will better describe the journey from when a clinician first suspects a person has cancer through diagnosis to when they first receive treatment. A more accurate picture of the experiences of all cancer patients will drive continuous improvement in the way their care is delivered and speed up treatment times. It also provides improved opportunity to standardise prehabilitation and supportive care services.

For primary care referrals there will be little change except the clock will start at the date the GP sent the referral rather than receipt of referral by secondary care. For referrals via all other routes the clock would start from clinical point of suspicion, with as a minimum the point being the same as NG12 NICE Guidance<sup>7</sup> on suspected cancer.

**The point of suspicion is when a clinician refers a patient or requests a test concerned a patient may have cancer. For screening it is the abnormal test report or colposcopy procedure.**

Specific examples are demonstrated in table 1.

## **Guiding principles**

All patients suspected of having a new primary cancer will be entered onto the pathway. This includes patients who have had a previous cancer and

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<sup>7</sup> [Link to NICE guidance](#)

are now suspected of having a different primary (a new cancer). Waiting times for subsequent treatments and recurrent disease will be recorded and reported via waiting times for specific treatment modalities and not part of the SCP.

- Recording and reporting of pathways will reflect the actual time experienced by patients.
- The reporting of cancer waiting times will drive continuous improvements in the pathway systems.
- The level of suspicion that '**starts the clock**' should be determined by the appropriate clinician **but should be in keeping with evidence based referral guidelines NICE NG12** and practical scenarios described below.
- All healthcare professionals should be familiar with the typical presenting features of cancers, or know where to obtain NG12 guidance, and be able to readily identify these features when patients consult with them. **However, adherence to these criteria must not be used as a barrier to a patient entering the pathway where clinical suspicion exists.**

### **Practical application of the guiding principles**

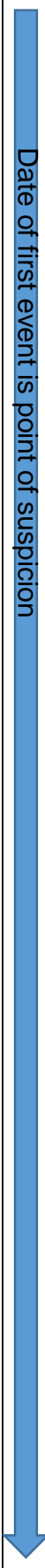
Health care professionals should make a suspected cancer referral to the appropriate MDT as soon as a diagnosis of cancer is suspected.


Discussion with a cancer specialist should be considered if there is uncertainty about the interpretation of symptoms and signs, and whether a referral is needed.

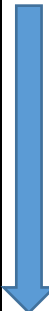
The point that the suspicion of cancer first arises is an individual clinical decision, not an administrative decision. However once this decision has been made by the clinician, the following guidance and pathway start dates as shown in table 1 should be used by health boards to designate the exact date that the suspected cancer pathway commenced.

**Please remember when using the below table it is the date of the first event that needs to be captured as point of suspicion**

### **Table 1**

Examples of first clinical suspicion of cancer	Recording the patient's entry onto the suspected cancer pathway – day 0	Pathway entry ***	Date of first event is point of suspicion 
Referral from primary care	Date referral is sent from primary care to the health board	Referral from GP Eye care services Dental services	
Primary care referral/request direct to test suspecting cancer (2 week rule)	Date referral/ test request sent from primary care to the diagnostic department	Referral from GP Eye care services Dental services	
Referrals from all Screening services: Breast Test Wales Bowel Screening Cervical Screening	Screening services will define the Point of Suspicion (as detailed in annex) and provide this patient data to HBs in a timely manner	Screening referral Breast Test Wales Bowel Screening Wales Cervical Screening Service Other screening service (NOT breast, bowel or cervical, such as AA screening)	
Receiving clinician suspects cancer in a referral (on vetting) not originally referred as 'suspected cancer' within secondary care (routine or urgent referral)	Date referral originally made by primary care	Referral from GP Eye care services Dental Services	
Receiving clinician receives additional information and suspects cancer in a referral not originally referred and vetted as 'suspected cancer' within secondary care (routine or urgent referral)	Date additional information was sent through to secondary care	Referral from GP Eye care services Dental Services	
Outpatient appointment not originally referred as 'suspected cancer' (routine or urgent referral)	Date of outpatient appointment where clinician suspects cancer due to new information or symptoms and 'upgrades' referral to suspected cancer pathway	Out-patient upgrade	

A&E attendance/ Medical Assessment/ emergency admission	Date patient assessed as suspected cancer by a clinician (documented in clinical records)	A&E / Medical Assessment/ emergency admission	Date of first event is point of suspicion 
Referral from one clinician to another within secondary care, including referrals from differing Health Boards and organisations. Velindre Trust would be an example of a differing organisation referring to other HB	Date of referral i.e. date of referral letter, if symptom has instigated referral to another speciality with no prior diagnostic test.  or:  Date of test/procedure performed which indicates a suspicion of cancer or a diagnosis of cancer - an incidental finding	Consultant Internal  Consultant External  Other healthcare professional e.g. such as CNS  Referral following diagnostic (if incidental finding)	
Referral from private health care clinician or organisation	Date referral sent from private organisation	Other healthcare professional	
Assessment of ward patient who has new suspicious symptom that needs investigating when admitted for other reasons unrelated to initial admission, or admitted for routine issues.	Date patient assessed as suspected cancer by clinician and documented in notes and requests specialist cancer opinion or test	Ward referral	
All diagnostic imaging which is suspicious of a diagnosis of cancer whereby the original referral or request was not suspicious of cancer I.e. incidental finding	Date of scan/procedure	Referral following diagnostic - Imaging	
All endoscopy procedures which are suspicious of a diagnosis of cancer whereby the original referral or request was not suspicious of cancer I.e. incidental finding	Date of procedure	Referral following diagnostic - Endoscopy	

All pathology samples such as: tissue biopsy and cytology whereby the original referral or request was not suspicious of cancer I.e. incidental finding	Date of sample/procedure	Referral following diagnostic – Other	
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**\*\*\* please note pathway entry is defined in tracker 7 as source of suspicion**

### **Further guidance**

For blood tests that raise the suspicion of cancer in primary care e.g. tumour markers, suspected cancer referral and/or further diagnostic tests should be informed by the NG12 guidance with the point of suspicion being defined in the table and text above.

If a patient is started on a SCP within one tumour site group however, following investigation results indicate the diagnosis<sup>8</sup> falls under a different tumour site group, the ‘point of suspicion’ date, should remain unchanged from the original date initially captured.

If a patient is referred as a ‘suspected cancer’ via rapid access referral route however, referral is downgraded at vetting or outpatient appointment, then following investigation such as biopsy, within 26-week time frame is found to be cancer, the original date of referral is the point of suspicion.

### **Resolution of uncertainties regarding the pathway start date**

There will be queries regarding individual patients and/or patient cohorts with respect to date the clock should start.

WCN has implemented a process whereby national advice will be sought and advice given. These will be collected and on an annual basis used to update and refine these guidelines.

<sup>8</sup> So long as the original symptoms relate to the diagnosis and are not an incidental finding which would start a new pathway (see example in Appendix 2).

For these enquiries or any further advice please contact:  
[singlecancerpathway@wales.nhs.uk](mailto:singlecancerpathway@wales.nhs.uk)

**SCP POS Annex 1**

Referral from Breast Test Wales	Date of validated abnormal mammogram report that initiates return for further test/s (date of arbitration or consensus)
Referral from Bowel screening	Date that the lab validate a positive FOB/FIT test
Referral from Cervical screening	<p>1. Date of validated high grade urgent smear report – this is the date of validation of high grade urgent result not the date the smear was taken.  The definition of the result is: -</p> <ul style="list-style-type: none"> <li>a. Severe dyskaryosis (? invasive squamous carcinoma)</li> <li>b. Glandular neoplasia of endocervical origin</li> <li>c. Glandular neoplasia of non-cervical origin</li> </ul> <p>2. Date of validated biopsy report where cancer is confirmed</p> <ul style="list-style-type: none"> <li>a. Microinvasive or invasive carcinoma</li> <li>b. NOT included 'carcinoma-in situ'/CGIN/SMILE</li> </ul> <p>3. Date of colposcopy procedure when cancer is suspected</p> <ul style="list-style-type: none"> <li>a. Date of colposcopic impression of? invasion recorded on Canisc</li> </ul>

## Appendix 2:

### Patient scenario/pathway examples

#### Pathway Start

##### Watch and Wait

For some patients, initial tests suspecting cancer do not confirm cancer and according to site specific guidance may have that pathway closed. These patients have a period of monitoring known as a 'Watch and Wait' whereby it is feasible to repeat the test following a set time frame (usually protocol driven). Following the subsequent test if a cancer is found therefore this patient has a new pathway start episode.

An example of this would be a patient that on an initial CT had a lung nodule. Following clinical guidance, the CT would be repeated and if changes are then found in the nodule that suggest malignancy this should start a new pathway.

##### Incidental finding

If a patient is started on a SCP within one tumour site group however, following investigation results indicate the diagnosis falls under a different tumour site group, the 'point of suspicion' date, should remain unchanged from the original referral date. The exception to this is where the diagnosis is unrelated to the initial referral and would come under incidental finding.

As an example:

Scenario 1 – A patient referred to ENT with a neck lump (e.g. head and neck cancer pathway) has a diagnosis of lymphoma following biopsy by ENT and the patient is referred to haematology for treatment (e.g. haematology pathway). In this scenario the POS remains the original referral date as the symptoms relate to the final diagnosis although a different tumour site.

Scenario 2 – A patient referred to gynaecology with post-menopausal bleeding (e.g. gynae cancer pathway) is referred by the consultant



gynaecologist who is concerned about the patient's sun-damaged skin on her face to dermatology. The outcome of the gynae investigations are benign but the patient is diagnosed by dermatology with a melanoma (e.g. skin cancer pathway). In this scenario the symptoms the patient was originally referred with have nothing to do with the cancer diagnosed and the POS for the skin cancer pathway is the internal referral from the gynaecologist to dermatology.

## **Pathway Stop**

### First Definitive Treatment (FDT)

The first definitive treatment should be agreed with the clinician responsible for the patient's management plan. This will be a clinical judgement.

The FDT is normally the first intervention which is intended to remove or shrink the tumour. Where there is no definitive anti-cancer treatment planned almost all patients will be offered a palliative intervention or palliative care (e.g. symptom control), which should be recorded for these purposes.

If the FDT is *surgery* record the date on which the first procedure took place, whether done on an inpatient or day case basis.

If the FDT is *chemotherapy and/or anti-cancer treatment (including hormone/endocrine/immunotherapy)*. Record the date on which the first dose of the drug is administered to the patient, or the date on which the prescription of the drug is dispensed to the patient if self-administered.

If the FDT is *radiotherapy* record the date on which the first fraction of radiotherapy for this prescription is administered to the patient.

If the FDT is *support or symptom control from specialist palliative care*, record the date of the first treatment/support from specialist palliative care.

If the FDT is *active monitoring*, record the date of the consultation on which this plan of care was agreed with the patient.

### Emergency treatment

If a patient is admitted as an emergency and undergoes immediate surgery, this would be classed as the FDT, with cancer confirmed on the histology as a result of this surgery. In this case the date of FDT would be the same date as the diagnosis date.

### FDT before pathology sampling

In some instances, FDT may occur before a tissue sample for histology is obtained, such as emergency radiotherapy for cord compression. This will result in a negative waiting time which always needs to be recorded as zero.

### Treatment Combinations

It may be useful to consider the various types of primary “treatment package” that different patients may receive:

- Many patients will receive a single treatment modality aimed at removing or eradicating the cancer completely or at reducing tumour bulk (e.g. surgery, radiotherapy or chemotherapy). In these cases, the definition of FDT and the start date are usually straightforward.
- Some patients will receive a combination of treatments as their primary “treatment package” (e.g. surgery followed by radiotherapy followed by chemotherapy). In these cases, the FDT is the first of these modalities to be delivered, and the date is the start date of this first treatment.
- Some patients will require an intervention which does not itself affect the cancer to be undertaken prior to the delivery of the anticancer treatment(s) – to enable these treatments to be given safely. As these interventions form part of the planned “treatment package” for the patient it has been agreed that the start date of the enabling intervention should be taken as the date of first definitive treatment. See section below for examples.

## Enabling Treatments

Work is currently ongoing to define a list by tumour site of all enabling treatments that can be considered as FDT. These guidelines will be updated as and when that information is agreed. Examples of enabling interventions are:

- colostomy for bowel obstruction
- insertion of oesophageal stent
- non-small cell lung cancer (NSCLC) stent
- ureteric stenting for advanced cervical cancer

## Palliative interventions

Others will undergo a clearly defined palliative intervention, which may be the same procedure noted in the enabling interventions above. However, patients will **not** then receive any specific anticancer therapy. For these patients the start date of this intervention should be recorded as the date of first treatment.

## Palliative Care

- Some patients will not receive any anticancer treatments but are referred specifically to a specialist palliative care (SPC) team. For these patients the date of the first assessment by a member of the SPC team is to be taken as the date of the first definitive “treatment”.
- Some patients will receive both anticancer treatment (e.g. radiotherapy) and a specialist palliative care assessment. In this instance the date of

The anticancer treatment is to be taken as date of first definitive treatment.

- Finally, some patients do not receive any specific anticancer treatment/intervention and are not referred to a SPC team. Where the patient is receiving symptomatic support and is being monitored these patients should be classified as undergoing “Active Monitoring”. Some patients may require general palliative care including symptom control – given under the care of GPs and/or oncologists. For patients

undergoing active monitoring the date of first treatment is the date their care plan is discussed between clinician and patient.

## **Pathway continue**

### Health Optimisation

Optimisation of a patient's physiological condition in readiness for FDT should **not** be considered as FDT and as such will not stop the pathway. Examples would be nutritional feeding or prehabilitation. These should be considered if appropriate early in the patient's pathway at referral, or while the patient is having diagnostic and staging investigations rather than near the end of their pathway prior to treatment.