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Guidelines for Managing Patients on the Suspected Cancer Pathway

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Contents

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 wcn.walescancernetwork@wales.nhs.uk. Operational issues will be addressed at the Cancer Operational Managers Group. Any queries that require clinical input should be submitted to the relevant Clinical Reference Group via the cancer network e-mail address: wcn.walescancernetwork@wales.nhs.uk. The National Strategic Clinical Network for cancer will maintain a log of queries and responses. This guidance will be reviewed at least annually.

This updated guidance (April 2024):

- Clarifies reporting responsibilities for incidental findings,
- Provides further clarity on procedures that qualify as first definitive treatment (FDT) in Annex 2.
- Addresses accessibility issues.

Background

1. In December 2020, a major change to the management of suspected cancer patients was introduced. A single, 62-day Suspected Cancer Pathway (SCP) was introduced, replacing the Urgent Suspected Cancer and the non-Urgent Suspected Cancer pathways. Further information can be found at: Wales Cancer Network - Single cancer pathway
2. The achievement of the cancer target is the responsibility of NHS Wales as set out in the quality statement for cancer. The underlying principle of the suspected cancer pathway is that patients should receive excellent care without delay.
3. This document sets out the rules to ensure that each patient's pathway waiting time is consistent and unnecessary delay does not occur as patients pass between clinical teams and organisations.
4. This document supersedes all previous guidance.

Cancer Waiting Time Target Definitions

5. The waiting time for patients on the SCP starts at the point at which cancer is suspected (See Point of Suspicion (POS)[1] guidelines) and ends at the start of first definitive treatment.
6. 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

7. NHS organisations should apply cancer waiting times in a consistent and fair manner in line with the Health and Social Care (Quality and Engagement) (Wales) Act 2020[2].
8. Patients should be managed with the aim of starting treatment at the earliest clinically appropriate time.
9. The performance threshold allows for patients who choose to delay their pathway as well as delays caused by clinical reasons or delays caused by highly complex pathways.
10. 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

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

Care for those with the greatest health need first

12. Clinical need should dictate the appropriate waiting time for any cancer pathway and the prioritisation of available capacity. The cancer waiting time target should not distort clinical urgency.

Public and professionals are equal partners through co-production

[1] See Annex 1
[2] Health and Social Care (Quality and Engagement) (Wales) Act 2020

13. The concept of an 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. The NHS will be required to deliver high quality care within the target time and enable patients to make informed choices about their treatment options. Patients will be expected to make themselves available for appointments within reasonable timescales and at sites where the service is delivered.

14. 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. This must be fully documented on the patients notes.

Reduce inappropriate variation through evidenced based approaches

15. Local pathways should comply with the national optimal pathways (where these are available) and waiting time guidance. Health boards should monitor and address unwarranted variation in pathway delivery.

Scope of the targets

16. The CWT applies to patients with a newly diagnosed cancer, including patients who first present with metastatic cancer.

17. 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[3].

18. Treatment for recurrence of cancer (i.e. a recurrence of the original primary cancer at a secondary site) is excluded from the CWT targets but will still be recorded in NHS Wales systems.

19. All patients under 16 years at date of referral should be grouped as children's cancer; all others are grouped as adults.

[3] Previously only the first instance of SCC would be included in cancer waiting times reporting. Now all instances of SCC primaries should be included.

20. The target applies to all patients referred and treated in NHS Wales. It includes independent providers contracted by NHS bodies for cancer investigation and treatment regardless of route to diagnosis.

21. 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.

22. 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. The target does not apply to Welsh residents who access independent healthcare themselves or who are referred directly to independent healthcare providers by their GP.

23. Where a patient is initially seen by a 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.

24. Where a patient is initially seen by the NHS but then chooses to have diagnostics privately and return to the NHS for treatment, the NHS must communicate with the patient that their pathway will be closed from the date the patient informs them 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.

Clinical responsibilities

25. Clinicians should aim to comply with national waiting time policies for cancer when delivering cancer pathways and work with cancer managers to improve the efficiency of pathways.

26. Healthcare professionals must be aware of national requirements and organisational policies in respect of waiting times. Clinicians should apply their judgement to the prioritisation of the available healthcare resource according to the clinical urgency of

those waiting on the suspected cancer pathway and those waiting on non-cancer pathways. They need to be actively aware of their own current waiting times and use this to discuss options and potential waits for their patients along their pathway.

27. Clinicians should ensure that their actions promote the principle of patients waiting the shortest possible clinically appropriate time for treatment.

28. Clinicians should work as a multi-disciplinary team in the management of patients but should not allow the timing of MDT meetings to unnecessarily delay treatment.

29. Clinicians should aim to comply with national optimal cancer pathways, recommended clinical best practice and standardised treatment regimens unless contraindicated, contrary to patient choice or part of a research trial.

30. Clinicians must make contemporaneous records of discussions and decisions and include reasons for deviations from recommended clinical practice in the patient's clinical record. Decisions should be made in a timely manner, and any onward referrals be completed promptly, according to local/national guidelines and optimal pathways, and include adequate information to allow the receiving clinician to initiate appropriate interventions with the minimum of delay. Referrers must ensure that the patient is aware and is in agreement for a suspected cancer referral to be made.

31. Clinicians must ensure patients are kept up to date about their care pathway and are supported to make individualised choices about their treatment.

32. Clinicians should consider the value of interventions and discuss with the patient the likely outcome of treatment options.

33. Clinicians are responsible for actively managing patients on a cancer pathway waiting list and a key aspect of waiting list management is to manage lists so as to minimise harm to patients waiting. New clinical decisions should be taken when the known risk changes to minimise harm to the patient. The materialisation of a risk that is known to the patient and clinician, in itself would not necessarily trigger the duty of candour[4].

34. If a clinician has a suspicion that a patient may have, or be at risk of, coming to harm due to delays to the pathway it is their responsibility to raise that concern using the local 'putting things right' policies and the National Reportable Incident system.

35. The duty of candour will be triggered if the reason a patient comes to harm is "unexpected or unintended" and that harm is more than minimal. (See the NHS Duty of Candour for more details[4])

36. 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.

37. 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

38. The suspected cancer pathway begins at the point of suspicion of cancer (see Point of Suspicion (POS)[5] guidelines).

Referrals

39. When a patient is referred from primary care (including optometry and dentistry) the pathway will start on the date the referral is made.

40. Clinicians in primary care should optimise the use of available tests/tools to support the assessment of patients prior to referring the patient.

41. The referrer needs to communicate to the patient that they are being referred with suspected cancer (as per national guidance) and inform them of the urgency of the subsequent investigations; contact details should be validated and included in the referral.

42. When two cancers are concurrently referred into secondary care, they both remain on the SCP pathway as two separate cancer pathways.

[4] The NHS Duty of Candour
[5] See Annex1

43. 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 greater 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 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 60 consecutive days and a new colorectal pathway started when the patient is available again.

44. If a patient is referred as a 'suspected cancer' but downgraded at vetting or outpatient appointment and is then subsequently found to have cancer following investigation such as biopsy, the original date of referral is the point of suspicion.

45. If a patient is started on a SCP within one cancer site group but following investigation results indicate the diagnosis[6] falls under a different cancer site group, the 'point of suspicion' date should remain unchanged from the original referral date.

46. Referrers should seek the consent of the patient to be contacted by the health board by such means as text, email, video-call or telephone and indicate if consent is given for this, and this should be included within the referral information.

47. The NHS must ensure that patients are seen by the most appropriate individual once the referral has been received and accepted.

48. The NHS should provide up-to-date information to patients relating to the pathway that will be followed, the likely waiting time and the locations the service will be delivered from. Discussions should also be supported by written information for patients either provided during consultation or by signposting where they can get additional

[6] 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).

information. Health boards should have systems in place to keep this information up-to-date and available to referrers.

49. 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.

50. When the NHS directs a referral to the wrong team, the clinician receiving the referral is responsible for forwarding on the referral at the earliest possible time to the appropriate clinician and the waiting time does not stop during this time.

51. 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 waiting time clock will continue whilst the information is obtained.

52. Secondary care should work with primary care to ensure good quality information flows between the two teams to support effective patient referral practice and joined up supportive care. This should include clinical information that will support prehabilitation requirements and patient optimisation prior to treatment, such as anaemia status and chronic condition status (eg, diabetes).

53. When the patient transfers between organisations or teams, it is the responsibility of the referrer 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.

54. The receiving organisation must ensure that the clinically communicated PSD is correctly used and captured in the patient administration system (PAS).

55. 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 pathway start is defined in the POS document[7].

[7] See annex 1

56. 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.

57. 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 reviewing the referral information. The pathway start date is defined in the POS document.

58. 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 SCP commences from the date the upgrade is requested. It is important that patients are informed of any status change either upgraded or downgraded referrals to manage their expectations.

59. A referral may be downgraded by the specialist when reviewing the referral information. The 26-week RTT target will then apply from the point the referral was received in secondary care. This decision and the reasons should be communicated to the referrer and the patient. (See also point 44)

60. Where a patient is admitted for urgent treatment outside of their health board of residence, for example following trauma, and through diagnostic testing cancer is suspected it is the responsibility of the treating health board to agree with the health board of residence the reporting responsibilities for the patient. If agreed the patient should be referred with a suspicion of cancer to the health board of residence with the POS (the date of diagnostic testing) clearly noted.

Booking processes

61. 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.

62. 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.

63. 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.

64. 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.

65. 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).

66. Each attempt to contact the patient under the booking processes must be recorded and made available for subsequent audit.

Direct booking

67. 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.

68. 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

69. 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.

70. 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.

71. 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.

72. 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

73. If the patient declares themselves as unavailable for the time period in which the offers are being made, and this is over 60 consecutive days, then they should be informed their pathway will stop and a new pathway started when they declare themselves available.

Could not attend (CNA)

74. 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.

75. 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.

76. 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).

77. 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.

78. If a patient makes themselves unavailable for a period of 60 consecutive days 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)

79. If the patient does not attend an appointment without giving notice, the patient should be contacted to re-arrange the appointment.

80. 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*)

81. An outcome must be recorded within the information system for every decision point in the pathway, whether the patient is present or not.

82. The defined outcome will fall into three categories: clock start, continue or stop.

83. 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.

84. CWT performance is the waiting time from referral to start of first definitive treatment without any adjustments.

Pathway continue outcomes

85. 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.

86. If an appointment is cancelled by the organisation, the pathway will continue, and a new appointment must be booked as soon as possible.

87. All referrals within a cancer pathway to diagnostic tests, therapy services or anaesthetic assessment will continue the pathway.

88. When a patient is referred from an NHS organisation to an independent sector organisation as part of their NHS pathway, the pathway will continue.

89. Where responsibility for a patient's care is transferred between consultants for the same condition, the pathway will continue.

90. 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

91. If a patient is unavailable (for medical or social reasons) to move on to the next stage of the pathway for a period of 60 consecutive days 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.

92. 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 60 consecutive days 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)

93. 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.

94. If FDT is surgery, the pathway will stop on the day the treatment (operation) was undertaken, whether done on an inpatient or day case basis.

95. 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.

96. 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.

97. If FDT is only Specialist Palliative Care[8], the pathway will stop on the date of the first treatment/support meeting.

98. A purely diagnostic procedure, including biopsies and endoscopic resection, does not count as treatment unless the procedure is curative and not just diagnostic, for example the tumour is effectively removed by the procedure. The pathway will stop

[8] See Annex 2 for more detail on SPC including FDT for patients receiving palliative support not through SPC teams.

on the day of 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.

99. First treatment refers to the FDT, some pathways may require preparation for that treatment, it is the start of the clinically agreed definitive treatment that stops the clock and not planned preparation.

100. 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

101. 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.

102. 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[9]. Active surveillance is for patients who have a cancer diagnosis confirmed.

[9] 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.

Communicating the diagnosis to a patient

103. 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.

104. Reasonable forms of communication with patients to confirm cancer include:

- direct communication with the patient, over phone, video or similar.
- face-to-face communication at an outpatient appointment.

105. The following are not appropriate means of relaying a cancer diagnosis:

- written communication by letter, or by email.
- Text/SMS message

106. 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.

107. 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

108. 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.

109. Health boards must ensure that appropriate systems are in place to capture the information necessary to meet the requirements for reporting.

110. 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 suspected of coming to harm should be reported through the National Reportable Incident and local 'putting things right' policies followed in line with the duty of candour.

Accountability for monitoring and reporting CWT

111. The health board receiving and accepting the patient's initial cancer referral or request for test is responsible for reporting the patient's CWT. 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. Powys residents will all be referred to another health board, it is the receiving health board that will report that wait.

112. 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.

113. 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).

114. 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.

115. 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 from secondary care for treatment outside NHS Wales will be included in CWT reporting.

Accountability for performance

116. 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.

117. 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.

118. Where an incidental finding occurs outside of a patients' health board of residence it is down to the organisation to agree with the health board of residence how to progress the patient. If agreed the patient should be referred to the health board of residence with a suspicion of cancer (see point 60) and they will be responsible for reporting the patient wait. If it is in the patients' best interest to remain in the care of the organisation that discovered the incidental finding, then both organisations need to agree the roles and responsibilities for reporting the patients' wait.

119. 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.

120. 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.

121. 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.

122. 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 supercedes 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[10] 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 are now suspected of having a different primary (a new cancer). Waiting times for subsequent treatments and recurrent

[10] Link to NICE guidance

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 ***
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
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

***** 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[11] 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.

For these enquiries or any further advice please contact:
wcn.walescancernetwork@wales.nhs.uk

SCP POS Annex 1

[11] 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).

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 FIT test
Referral from Cervical screening	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: - a. Severe dyskaryosis (? invasive squamous carcinoma) b. Glandular neoplasia of endocervical origin c. Glandular neoplasia of non-cervical origin 2. Date of validated biopsy report where cancer is confirmed a. Microinvasive or invasive carcinoma b. NOT included 'carcinoma-in situ'/CGIN/SMILE 3. Date of colposcopy procedure when cancer is suspected a. Date of colposcopic impression of? invasion recorded on Canisc

Appendix 2:

Patient scenario/pathway examples

This section of the Cancer Waiting Times (CWT) guidance sets out the clear guidance concerning enabling treatments, clarifying which enabling treatment results in a pathway close and which site specific treatments are not classed as a first definitive treatment and therefore will not close the pathway.

This section has been developed in consultation with the National Strategic Clinical Network for cancer and the Cancer Site Groups across Wales. Whilst this section endeavours to provide guidance for most clinical scenarios, teams should consult with the patient's clinical team if there is any confusion as to the intent of a procedure.

Definition of Terms

A treatment is an intervention intended to manage the patient's disease, condition or injury and to avoid further intervention. It is a matter of clinical judgement, in consultation with the patient.

Curative treatment – Active treatment where the intent is to eradicate the cancer, includes adjuvant, neo-adjuvant and radical.

Palliative Treatment –Active treatment where part of the intent is to pro-long life.

Best Supportive Care – this refers to treatment aiming to improve and/or maintain a patient's quality of life.

Active Monitoring – Also referred to as Watch and Wait, where no active treatment is currently needed, but the patient will continue to be clinically monitored for signs of disease progression.

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

Palliative care for any patient who is subsequently going to receive active treatment, is not considered an FDT unless they decline active treatment options and wish to have only palliative care.
Surgical biopsies for diagnostic purposes are not routinely considered an FDT. However, in some cases the tumour is effectively removed by the procedure, i.e. considered curative or just requiring adjuvant ablative therapy – this should be confirmed by a pathology report. Table 2 in the health optimisation section below provides some site specific examples of this.

Enabling treatments have been developed / reviewed against the following principles:

- The enabling treatment is clinically necessary prior to cancer treatment.
- The enabling treatment is not necessary because of a delay in cancer treatment.

- The enabling treatment causes a clinically significant delay of more than one week before the commencement of cancer treatment.
- The enabling treatment is targeted towards a specific group of patients.

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 know 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 continue

Enabling Treatments

Enabling treatments allow a patient to progress on the pathway but as they do not address the cancer itself cannot be classed as FDT. The table below contains examples of enabling treatments that do not count as FDT and as such do not close the pathway.

Table 1: The following Enabling treatments are NOT classed as First Definitive Treatments

Tumour Site	Procedure
All Sites	Iron Tablets
	Monofer or ferinject iron infusion
	Peripherally inserted central catheter line insertions
	Cystodiathermy
	Placement of rectal spacer prior to radiotherapy
	Dental extractions prior to radiotherapy
	Tracheostomy prior to Radiotherapy

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.

Table 2: The following site specific procedures are NOT classed as First Definitive Treatments.

Tumour Site	Procedure
Breast	Sentinel Lymph Node Biopsy - this is a diagnostic staging procedure to determine whether the cancer has spread to the lymph nodes
	Aromatase Inhibitors or Tamoxifen hormone treatment can only be classed as First Definitive Treatment if it is to be the sole treatment modality, the patient has refused/is unfit for surgery, or the treatment plan specifies that neo-adjuvant endocrine therapy is needed for a minimum period prior to subsequent treatment.

Tumour Site	Procedure
Colorectal	Surgical biopsy or polypectomy (EMR, ESD), for diagnostic purposes, unless the tumour is effectively removed by the procedure with no additional or only adjuvant therapies required (this will usually only be known with the pathology result).
	Colostomy (e.g. for bowel obstruction) where this is necessary prior to definitive treatment or due to the length of wait for definitive treatment.
	Stenting (e.g. colonic stent to relieve an obstruction), where this is necessary prior to definitive treatment or due to the length of wait for definitive treatment).
Gynaecology	Cone or loop or LLETZ biopsy /hysteroscopy/ colposcopy/ vulvoscopy if diagnostic in intent only – however, if therapeutic in intent (i.e., if the intention of the procedure was to remove the tumour) then these would count as first treatment irrespective of whether the margins were clear. If the intention was diagnostic but the tissue was found to be malignant the procedure could count as first treatment if the tumour had effectively been removed by the excision and no further treatment or only adjuvant treatment was required.
	Removal of polyps for diagnostic purposes – however, if the tissue was found to be malignant the procedure could count as first treatment if the tumour had effectively been removed by the excision e.g. considered curative with no additional or only adjuvant therapies required.
	Removal of para-aortic nodes before a patient starts radiotherapy or chemotherapy - however, if clinically involved nodes are having to be de-bulked prior to radiotherapy, this could be classed as first treatment.
	Ileal conduit urinary diversion surgery to treat a bladder problem prior to active treatment (e.g., chemoradiation).
	Removal/draining of ascites prior to chemotherapy, unless no other active treatment is planned.
	Mirena insertion at the time of hysteroscopy is not considered a first definitive treatment if definitive treatment is hysterectomy.
	Stenting e.g. where this is necessary prior to definitive treatment or due to the length of wait for definitive treatment.
Haematological	Removal or biopsy of Lymph Nodes is done to establish a diagnosis of Lymphoma and there is likely to be additional disease throughout the body that will need active treatment. In rare circumstances this may remove all the disease, so would be considered an FDT, but this should be confirmed with a PET showing no residual active disease.
	Blood transfusions – unless a patient has no other active treatment planned, in this case the transfusions would be classed as palliative treatment.
Lung	Drainage of a pleural effusion if further anti-cancer treatment is planned.
	Pleurodesis if further anti-cancer treatment is planned.
	Mediastinoscopy, unless the excised tissue was found to be malignant and the tumour had effectively been removed by the excision irrespective of whether the margins were clear – this is unlikely.
	Stenting of the airway or superior vena cava if further anti-cancer treatment is planned.

Tumour Site	Procedure
	Endobronchial debulking of tumour (e.g., laser, cryotherapy, diathermy etc) if further anti-cancer treatment is planned.
	Video Assisted Thoracic Surgery (VATS) biopsy for diagnostic purposes unless procedure could be considered as de-bulking the tumour.
	Performance status improvement or Pre-habilitation, when active treatment planned.
	Organ specific optimisation (coronary stenting, dialysis etc), when active treatment planned.
Lung - Mesothelioma	Drainage of a pleural effusion if further anti-cancer treatment is planned.
	Pleurodesis if further anti-cancer treatment is planned.
	Interventional analgesia (e.g., nerve block or cordotomy) if further anti-cancer treatment is planned.
Skin	Sentinel Node Biopsy – this is a diagnostic staging procedure to determine whether the cancer has spread to the lymph nodes.
UGI - Pancreas	Insertion of pancreatic/biliary stent - prior to potential curative treatment.
	Insertion of pancreatic/biliary stent - for patients with mild obstructive jaundice (a serum bilirubin below 200 micromol/l) if local practice is that they do not require biliary stenting before resection if surgery and imaging are planned within 7-10 days.
UGI oesophago-gastric cancer	Enteral feeding including nasogastric/ gastrostomy/ jejunostomy prior to further active treatment.
	EMR for a staging procedure (diagnostic only) unless considered curative with no additional or only adjuvant therapies required (this will usually only be known with the pathology result).
Urology	Surgical biopsy for diagnostic purposes (unless the tumour is effectively removed by the procedure). This includes a TURBT procedure unless the tumour has been effectively treated and the patient is now on surveillance. This should be documented in the MDT meeting, which can protocolise decision for straightforward cases.
	LHRH is a first definitive treatment for patients with high risk and unfavourable intermediate risk localised prostate cancer, but not an appropriate first definitive treatment for low risk and favourable intermediate risk prostate cancer, who are to receive further active treatment.

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 endoscopic resection record the date on which the 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.

Table 3: *The following enabling treatments CAN be classed as First Definitive Treatments*

Tumour Site	Procedure
Brain	Dexamethasone, when described as palliative care with no other anti-cancer treatment being planned.
	Anti-Epileptic Drug treatment, when described as palliative care with no other anti-cancer treatment being planned.
	CSF Diversion Procedure (Shunt; Ventriculostomy) where indicated and appropriate, when described as palliative care with no other anti-cancer treatment being planned.
Colorectal	Colostomy where first palliative treatment if no further active treatment is planned.
	Stenting where first palliative treatment, if no further active treatment is planned.
Gynae	Stenting where first palliative treatment, if no further active treatment is planned.
Haematology	Antibiotics count as the start of treatment for some types of low-grade lymphoma (e.g. MALT Lymphoma) and antibiotic eradication therapy of anti-hepatitis C therapy for EZML (extra-nodal marginal zone lymphoma).
	Starting all-trans retinoic acid (ATRA) on suspicion of acute promyelocytic leukaemia.
	Starting oral hydroxycarbamide (or other 'enabling' agents such as oral etoposide or stat doses of cytarabine) in the setting of acute myeloid leukaemia requiring urgent cytoreduction.
	Commencing steroid pre-phase in treatment of acute lymphoblastic leukaemia (ALL).
	Commencing steroids upon diagnosis of myeloma, lymphomas prior to formal chemotherapy combinations.
	Commencing immunosuppressive treatments (e.g., ATG, cyclosporin) for hypoplastic myelodysplastic syndrome.
	Commencing non-chemotherapy immunomodulatory treatments such as androgens / danazol for myelofibrosis.
	Commencing rEPO for MDS where anaemia dominates, and chemotherapy is not required.
	Reducing immunosuppression for patients with PTLD (post-transplant lymphoproliferative disorder).
UGI- OG/HPB	Stenting where this will be the main treatment or prior to palliative chemotherapy, but not stenting to enable further definitive treatment, e.g., for jaundice followed by surgery in pancreatic surgery.
	Enteral feeding including nasogastric/ gastrostomy/ jejunostomy as part of primary palliative treatment.
UGI - Liver	Portal vein embolization prior to surgery for liver cancer (primary or secondary) to allow liver growth prior to surgery.

Tumour Site	Procedure
Urology	LHRH is a first definitive treatment for patients with high risk and unfavourable intermediate risk localised prostate cancer where this leads to a planned delay to further active treatment such as radiotherapy or surgery

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.

Specialist 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.