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For Action by: Chief Executives, Chief Operating Officers, Heads of information

Action required by: 1 December 2019

Sender:

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Enclosure(s): Letter from Olivia Shorrocks
Dear Colleagues

Consolidated Rules for Managing Cancer Waiting Times – September 2019

Please find attached the final version of the updated rules “CONSOLIDATED RULES FOR MANAGING CANCER WAITING TIMES - September 2019”.

These rules will replace all previous guidance with effect from 1st December 2019.

All patients who have started on their referral/diagnosis/treatment pathway prior to 1st December 2019 will continue to be monitored and reported on using the existing rules for cancer waiting times. This will remain for a maximum period of 6 months by which time we would expect all patients starting their pathway prior to 1st December 2019 to have completed their pathways by 31st May 2020.

The new rules will apply to patients beginning their pathway on or after 1st December 2019.

Please also note these rules apply to all cancer pathways, urgent suspected cancer (USC), non-urgent suspected cancer (NUSC) and single cancer (SCP) pathways.

Yours sincerely

Olivia Shorrocks
HEAD OF MAJOR CONDITIONS

We welcome receiving correspondence in Welsh. Any correspondence received in Welsh will be answered in Welsh and corresponding in Welsh will not lead to a delay in responding.
Consolidated Rules for Managing Cancer Waiting Times

September 2019

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Overview

Document Summary
This document provides guidelines relating to the management of cancer waiting times and the reporting of performance against the cancer targets. Any queries relating to the management and reporting of cancer waiting times will be addressed by a clinically guided advisory group who will also maintain a live data base of queries to supplement these guidelines. The advisory group can be contacted via the Wales Cancer Network e-mail:

singlecancerpathway@wales.nhs.uk

Target Development

1. Cancer Waiting Time (CWT) targets, were first introduced as part of the Service and Financial Framework (SaFF) targets in 2004/05. Since then the definitions and requirements for reporting CWT have been developed and modified. This document is a working document recording the current position of CWT reporting and as such is subject to change over time.

2. Since the original CWT targets were introduced a Single Suspected Cancer Pathway (SCP) has been developed and formally reported on from June 2019. Further SCP guidance can be found here:

   Wales Cancer Network | SCP Key Documents

3. The achievement of the cancer targets is the responsibility of NHS Wales.

4. The underlying principle of the cancer pathways is that patients should receive excellent care without delay.

5. Within the pathway waiting time, both the patient and the NHS in Wales have roles and responsibilities that are required to achieve this.

6. 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

7. The CWT standards for cancer are:

**Urgent Suspected Cancer (USC):** Patients referred from primary care with suspected cancer, fulfilling specific criteria and accepted as suspected cancer by site specific specialists in secondary care, should start treatment within 62 days of the receipt of the original referral. The performance measure for this pathway is 95% of patients referred with suspected cancer to have started first definitive treatment within the pathway target of 62 days.

**Non-Urgent Suspected Cancer (NUSC):** This is for all patients diagnosed with cancer by other referral routes. It is currently measured from the time the patient accepts their treatment plan, defined as the date of Decision To Treat (DTT)\(^1\), to start treatment, within a pathway target of 31 days. The performance measure for this pathway is 98% of patients starting first definitive treatment in the reporting month to have met the pathway target of 31 days.

A third pathway was formally introduced in June 2019. This is reported alongside the existing targets.

**Single Suspected Cancer Pathway (SCP)** measures CWTs from the **Point of Suspicion (POS)** of cancer until start of first definitive treatment for all newly diagnosed patients. It aims to ensure the majority of all patients presenting with a suspicion of cancer start treatment within 62 days of the POS. For current USC referrals there would be little change except the pathway would start at the date primary care referred the patient rather than receipt of referral by secondary care. For current NUSC routes to diagnosis the pathway would start from the date of clinical suspicion as defined in the SCP POS document.

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\(^1\) Date of Decision to Treat - The date upon which the decision to treat was confirmed between a designated member of the MDT and the patient.
It is anticipated that the SCP will in the future replace the other two cancer targets. No performance measure has been set for the SCP as yet but there is an expectation for continuous improvement during the implementation phase.

**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 all cancer targets. 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.

**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 performance measures 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 will 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 reinstatement.

Reduce inappropriate variation through evidenced based approaches.

16. The rules have been written to be robust and clear. Health boards will be expected to maintain appropriate governance structures to ensure that where there is flexibility within the rules, the spirit of the pathways is achieved. 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. At a later date, our intention is to report on Welsh patients treated in England. At present (August 2019) this is not possible. Discussions are taking place with NHS Digital to explore how this might be achieved. Until a solution is agreed, patients treated in England will be treated in line with the English cancer standards.

18. The cancer pathways cover 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.

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

20. 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 NUSC, USC and SCP pathway reporting, at the point of that referral back to the NHS. The date of suspicion is therefore the date of referral into the NHS.

21. 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 adjusted from the date the patient informs the Health Board they wish to have diagnostics privately to when they then inform the health board they are ready to complete their NHS pathway. The patient may choose to have additional tests to help them make a more informed decision about their treatment options, and as such this can be a form of adjustment for thinking/decision making.
22. 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.

23. 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 cancer as a new primary cancer\(^2\). (Exclusion footnote for Squamous Cell Carcinoma of skin)

24. Treatment for recurrence of cancer i.e. a recurrence of the original primary cancer at a secondary site is excluded from the CWT targets.

Clinical responsibilities

The responsibilities of clinical staff in monitoring cancer waiting times

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

26. 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.

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

28. 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.

29. Clinicians should make decisions in a timely manner, and ensure that any onward referrals are completed promptly, according to local/national

\(^2\) Squamous Cell Carcinoma- Most patients have a single lesion at presentation but a significant number will get more primaries over a period of time. Only one cancer care episode (i.e. one record) should be recorded for all the Squamous Cell Carcinomas.
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 referral to be made.

30. 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 phone or letter.

31. 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, whether those decisions are made in the presence of the patient or not.

32. 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 definitive treatment and as such ends the pathway.

**Referrals**

33. The USC cancer pathway begins 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 that the organisation receives the referral. For the SCP CWT the date the referral is made is the point at which the pathway starts. (If electronic referral is used the dates for both pathways should be the same).

34. The referrer needs to communicate to the patient that they are being referred as urgent, potentially with suspected cancer, 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.
35. When two cancers are concurrently referred into secondary care as USC’s, they both remain on their USC and SCP pathways as two separate cancer pathways.

36. When a patient is referred as a USC on suspicion of one cancer but during that care spell is diagnosed with another cancer (i.e. NUSC) of greater clinical priority. The NUSC will be treated first, but both pathways remain open. Medical adjustments may be applied to the USC pathway while the patient is receiving treatment for the NUSC. Both cancers should be reported under the SCP pathways but the USC and NUSC report on their respective pathways.

An example of this would be if a patient was referred in on a USC pathway 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 on a NUSC pathway. The lung cancer is determined by the teams as the clinical priority therefore this pathway (NUSC) will continue to treatment first. The colorectal pathway (USC) can have medical adjustments applied while the patient receives treatment for the lung cancer. Both cancers should be reported under SCP pathways but the USC and NUSC report on their respective pathways.

37. A patient who is not already on a USC pathway and is diagnosed incidentally with cancer should be reported under the NUSC and SCP pathways.

38. 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 36-week time frame is found to be cancer, the original date of referral is the point of suspicion.

39. 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 date initially captured.

40. 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 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.

41. 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 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.

42. 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.

43. 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.

44. 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.

45. Health boards need to work with primary care to ensure good quality information flows between the two areas to support effective patient care.

46. 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.

47. 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.

48. Only referrals from primary care (i.e. GP, Dental or Optometry) can be designated as USC referrals.

49. A referral is designated as a USC when a suspicion of cancer is stated by the referrer (from Primary Care) and confirmed by the specialist initially receiving the referral. The USC pathway starts the date the referral is received by secondary care. The SCP pathway starts from the date the referral is sent. Encouragement and use of electronic referral would result in the same date for both pathways.

50. If a referral which has not been made as a suspected cancer pathway is subsequently upgraded to a suspected cancer pathway by the specialist, the 62 days commence from the date secondary care received the referral, not the date the specialist reviewed the referral. Note for SCP reporting the pathway start is the date the referral is sent to secondary care, as opposed to received.

51. 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.

52. A referral from primary care 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 62-day target will apply.

53. 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.
54. 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 behind it should be communicated to the referrer.

55. When a USC referral is made to a clinician who does not treat the condition, it should be forwarded to the appropriate consultant. The 62-day pathway will continue.

**Booking processes**

56. The focus of the booking interaction should be on offering the first available date(s), due to the aim for a short pathway, although patient’s needs should always be considered as much as possible.

57. 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.

58. 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.

59. 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.

60. No organisation should be seeking periods of unavailability in order to meet targets. The focus of the booking interaction should be on offering the first available date(s), due to the aim for a short pathway, although patient’s needs should always be considered as much as possible.

61. 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).

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

Direct booking

63. Direct booking can take place in two ways. An appointment/test can either be booked in a face-to-face interaction with the patient or through a direct dialogue with the patient, phone/email and or text.

64. 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

65. 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.

66. 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.
67. When the organisation makes significant attempts (at least two methods of different contact) to contact the patient and they do not respond within two weeks, the patient will be paused while the organisation makes further efforts to contact the patient. The adjustment begins from the first failed attempt of contact and ends when contact with the patient is achieved or the patient is removed from the waiting list. This only applies retrospectively to patients who fail to respond within two weeks.

68. 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.

69. 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 pathway reset to 0, with the new pathway starting on the date contact is made. This should be communicated with patient and referrer for clarity on CWT targets.

Refusal of a reasonable offer

70. If the patient declares themselves as unavailable for the time period in which the offers are being made, the social unavailability rules will apply.

Could not attend (CNA)

71. 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.

72. 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.
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)

73. If a patient CNA within any stage of the pathway, a new appointment must be made as near to the date the patient states they are next available. An adjustment can be applied from the date of the CNA appointment through to the new appointment date.

Did not attend (DNA)

74. If the patient does not attend an appointment without giving notice, the patient should be contacted to re-arrange the appointment. An adjustment (cancer adjustment) can be applied to the CWT from the date of DNA to the next appointment date.

75. The DNA adjustment may be applied on a maximum of two occasions in any given pathway. If the patient DNAs for a third time or more, and the consultant responsible feels the patient should remain on the waiting list, the pathway should be paused and the clinician should write to the referrer and patient seeking clarification that they need to continue on the pathway. A two-week pause period should be applied to ensure that the pathway is reviewed and actioned in a timely manner. Only if this is confirmed by the referrer and the patient will they be reinstated on the waiting list and the pathway will be reset to 0 on the date of confirmation from the referrer and patient that they wish for the patient to remain on the pathway. They should restart at the most appropriate stage of the pathway based on their clinical need and their past pathway.

Attendance outcomes

(Example scenarios are available in appendix 1)

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

77. The defined outcome will fall into two categories: pathway continue or pathway stop.
78. 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.

**Pathway continue outcomes**

79. A pathway continue 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, treatment begins or patient refuses treatment or dies.

80. If an appointment is cancelled by the organisation, the pathway will continue, and a new appointment must be booked with no adjustment applied to the pathway for this change.

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

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

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

84. 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**

**First Definitive Treatment (FDT)**

85. **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.
86. If FDT is surgery, the pathway will stop after the surgical procedure has taken place, whether done on an inpatient or day case basis.

87. 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.

88. 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.

89. If FDT is specialist palliative care, the pathway will stop on the date of the first treatment/support meeting.

90. 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.

91. First treatment refers to the FDT and may not necessarily be the first planned treatment decided upon by the multi-disciplinary team.

92. A transfer of care between consultants for the treatment of the same condition will not stop the pathway. See Point 80.

93. When a patient is either socially or medically unavailable, the rules on unavailability for the cancer target should be followed and the pathway does not stop. See section on cancer adjustments.

94. 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 will be closely reviewed to ensure that delay due to trials is not a factor.
New pathway start

95. 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.

96. 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 1.

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

Cancer Adjustments

97. CWT pathways are reported based on closed completed pathways, and therefore any agreed appropriate adjustments (see below) are recorded retrospectively. All proposed adjustments need to be clearly recorded along the patient pathway to be applied when the pathway is closed and reported.

98. A patient may be adjusted from the waiting list when, due to either medical or social reasons, the patient is unable to move on to the next stage of the pathway. The adjustment will run for the period of unavailability. It is the role of the health board to stress to the patient the urgency of their treatment and to ensure they understand the consequences of any delays.

99. The period of adjustment will begin on the date of the notification of unavailability, and end on the date the patient is available or declared clinically fit to continue their pathway.

100. The maximum adjustment period is three months for a medical adjustment and six months for social adjustment. If the patient cannot return to the pathway following these adjustment periods, they should be removed.

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3 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.
from the waiting list and returned to the referrer. In exceptional circumstances if a new medical condition is found to have developed, the patient can be re-adjusted for an additional three-month period. In the case of pregnancy or in the case of treatment of a second primary of greater clinical priority, the adjustment period may exceed three months, providing the end date is recorded.

101. When the patient is adjusted for medical reasons, there must be robust mechanisms in place to deal with the reason for the adjustment. A plan must be in place with the aim that when the adjustment period ends, the patient will be medically fit.

102. When the patient is adjusted for social reasons, the total of six months may be made up of several individual periods of adjustment. The total cumulative adjustment across all stages of the pathway must not exceed six months. While it is the patients’ choice to suspend their pathway for social reasons it is the responsibility of the HB to communicate clearly to the patient the consequences of delaying their pathway and starting treatment.

**Adjustment for social reasons**

103. The pathway can be adjusted:

- When a patient has other commitments they wish to pursue prior to treatment or investigation (e.g. holiday)
- When a patient requests a period of time to think (e.g. to decide on treatment options). The pathway should be adjusted from the date the patient makes the request to the date the patient informs the service of its decision, either face to face or by phone or email.
- When a patient requests a second opinion before making a decision on treatment (the pathway does not stop if the clinician requires a second opinion). The pathway should be adjusted from the date the patient makes the request to the date the patient informs the service of its decision, either face to face or by phone or email.
104. Adjustments must be clearly recorded in the patient notes. The position of any patient adjusted must be reviewed regularly.

105. The pathway is not adjusted:
   When a patient chooses a treatment with a longer waiting time (e.g. robotic surgery rather than open surgery)
   A patient should not be adjusted once an admission date has been agreed, unless the date is later than normal due to the need to resolve other medical problems prior to treatment.

Adjustment for medical reasons

106. The pathway is adjusted when a patient is unavailable for a diagnostic or staging test or treatment due to another medical condition that needs to be resolved (e.g. cardiac event or pulmonary embolism).

107. Adjustments must be clearly recorded in the patient notes. The position of any patient adjusted must be reviewed regularly.

108. The pathway is not adjusted:
   When the Health Board is unable to offer treatment within the required timescales
   For a patient who requires repeat biopsies or scans because of uncertainty the first time round
   Once an admission date has been agreed, unless the date is later than normal due to the need to resolve other medical problems prior to treatment.

Recording and reporting

Reporting formats

109. 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.

110. Health boards must ensure that appropriate systems are in place to capture the information necessary to meet the requirements for reporting.
111. All patients who are not treated within the NUSC and USC targets should have a breach report completed detailing their pathway journey and outlining the lessons learnt and remedial actions taken within the health board. There is currently no requirement to complete breach reporting for SCP patients. All breach reports should be submitted to Welsh Government.

Accountability for monitoring and reporting CWT

112. The health board receiving and accepting the patients’ initial referral or request for test is responsible for reporting the patients 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.

113. All health boards involved in the diagnosis and treatment of the patient are responsible for monitoring the patients’ pathway and making the data available to the reporting health board.

114. 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).

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4 The exception to this is Powys Teaching Health Board which is responsible for reporting all patients’ pathways that occur exclusively within Powys or are commissioned in England. The reporting of Powys residents who are treated/diagnosed in other health boards will not change from existing rules and will be included in the other health boards reporting figures. This is to avoid the potential double counting of Powys residents.
115. 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.

116. 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 (England and Wales). 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. It is our intention to capture patients treated in England on the SCP, however systems and processes do not allow this at present. Discussions are underway with NHS Digital and this guidance will be updated when the systems to allow this are in place.

Accountability for performance

117. 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.

118. 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. (See footnote 3 on page 20).

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 patients 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 patients’ pathway remains with the health board who received the original patient referral.
120. Where NHS activity is commissioned from an English provider, the accountability for managing the patients 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 patients’ pathway remains with the health board who received the original patient referral.

121. Where a patient is not referred, but received initial consultation in England, the reporting should be covered by the resident health board.

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:

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.

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.

**Health Optimisation**

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

**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.

Examples of enabling interventions

- 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.

Examples of social adjustments

A patient is advised that potentially curative treatment involves significant risk of serious side effects (which may include peri-operative death). The patient wishes to be referred for a second opinion to see if they might avoid these outcomes but yet still achieve cure. The patient is suspended for patient reasons as they have made themselves unavailable for treatment whilst seeking a second opinion.

A patient is discussing their care-plan with a clinician and states (before any offer of an admission date is made) that they would like to take the holiday they have booked prior to treatment starting. As no offer of a TCI date had been made by the health board this can be classified as an adjustment for patient reasons. The period which the patient has made themselves unavailable should be adjusted out of the calculated waiting time. It is good clinical practice to advise the patient on the risks associated with delaying treatment to allow the patient to make an informed decision.

Examples of adjustment for medical reasons

Co-morbidities
Some cancer patients will have co-morbidities, which will require investigation and/or treatment prior to administering cancer treatment. For example, a cancer patient with angina may be referred for a cardiology opinion prior to treatment.

In this case the pathway will only stop if at the cardiology review the patient is declared medically unfit for cancer treatment at that time.

The pathway does not stop while the opinion is being sort.

The pathway does not stop if the opinion is that the patient is fit for cancer treatment.

Hence the pathway does not stop whilst an opinion on the co-morbidity is being sought.

**Concurrent Primary Cancers**

Some patients may present with two primary cancers at the same time and clinically a decision will be made to determine which one would take clinically priority in regards to treatment. This example would mean that two pathways are open and the primary with the lesser clinical priority can be suspended while the patient undergoes treatment for the other cancer. This should not delay the appropriate investigations being performed for the lesser priority cancer in a timely manner. An example of this may be in the instance an early colorectal cancer is diagnosed at the same time a lung cancer is diagnosed.

**Pregnancy**

If a patient is found to be pregnant during a cancer diagnosis, then an adjustment can be used as advised clinically.