National Cancer Waits Project

CANCER WAITING TARGETS – A GUIDE (VERSION 5)

Cancer Action Team NHS

Amendments from version 4 to version 5

The waiting times guide has been updated from version 4. Sections which have been amended are listed below.

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CANCER WAITING TARGETS – A GUIDE (VERSION 5)

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Introduction

1. The National Cancer Plan was published in September 2000. Within the Plan there are a number of commitments and targets relating to waiting times for treatment. This document provides answers to frequently asked questions about the 2001, 2002 & 2005 Cancer Plan targets:

- Maximum one month wait from urgent GP referral for suspected cancer to first definitive treatment for children's, testicular cancers and acute leukaemia by 2001.
- Maximum one month from diagnosis (DECISION TO TREAT DATE) to first definitive treatment for breast cancer by 2001.
- Maximum two month wait from urgent GP referral for suspected cancer to first definitive treatment for breast cancer by 2002
- Maximum two month wait from urgent GP referral for suspected cancer to first definitive treatment for all cancers by 2005 ("62 day target")
- Maximum one month wait from diagnosis (DECISION TO TREAT DATE) to first definitive treatment for all cancers by 2005 ("31 day target")

In addition there is also the existing two week waiting time standard:

- Maximum two week wait for an urgent GP referral for suspected cancer to date first seen for all suspected cancers.

There is an existing Q & A on "Achieving the two week standard: Questions and Answers" available at http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/Cancer/CancerArticle/fs/en?CONTENT_ID=4001800&chk=dpRNWQ

2. All these targets are being monitored through the national cancer waiting times database (CWT-Db). This document needs to read in conjunction with HSC 2002/005, the Data Set Change Notice 22/2002 and the Cancer Waiting Times User Manual detailed in references (page 36).

Part 1- Who is responsible for meeting the targets and returning data?

1.1 Who is responsible for meeting the targets and returning data for the Two Week Standard?

The trust that is commissioned to see patients following urgent GP referral for suspected cancer is responsible for meeting the two week wait standard. They are also responsible for returning data on these patients up to the date first seen and for explaining breaches of the two week wait standard.

1.2 Who is responsible for meeting the targets and returning data on the 31 day decision to treat to treatment target / 62 day urgent referral to first treatment target?

The trust commissioned to administer the first definitive treatment is responsible for meeting the targets on time to first treatment. They are also responsible for returning data on these patients to monitor the targets and for explaining breaches on existing standards (see below).
Some patients on the 62 day pathway are first seen under the two week standard at one trust and are then referred on to another trust for treatment. So, in this case both trusts are responsible for ensuring that the 62 day waiting time target is met. The Healthcare Commission assess the performance of both trusts in the care pathway in achieving the 62 day target, as part of the performance ratings.

PCTs are responsible for commissioning services in line with the 31 and 62 day targets for their patients and should track waiting times for their managed population through the Cancer Waits Database (CWT-Db). The Healthcare Commission also assess the performance of PCTs against achievement of these targets as part of the performance ratings. For further information on commissioning see para 1.5.

1.3 What information is required on breaches?

Detailed reports on breaches are required on all patients that wait longer than the target time and should include how long the patient waited, reason for the breach in the target and action put in place to prevent further breaches. The reason for the breach should still be recorded for a patient where there are good clinical reasons for the time to treatment exceeding the target time (see para 2.6).

1.4 How does the database support the Cancer Services Collaborative Improvement Partnership (CSC-IP)?

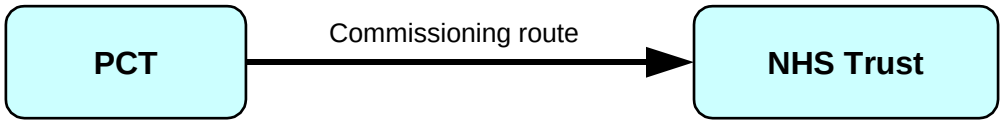
The database has been designed to support the service improvement work of the CSC-IP. It allows the collection of a small number of additional data items on cancer patients along the patient pathway, which the CSC-IP have shown are useful to service improvement.

1.5 Whose activity is it? Who is responsible for recording it?

Some questions have been raised about which trust code to record when a patient is first seen or receives treatment. In general this is straightforward, but there are circumstances where you will need to consider the commissioning route for the care.

There are many different structures that can apply to the ownership of commissioned activity and the information associated with it. These diagrams represent the different scenarios that could apply to these data stored on the CWT-Db.

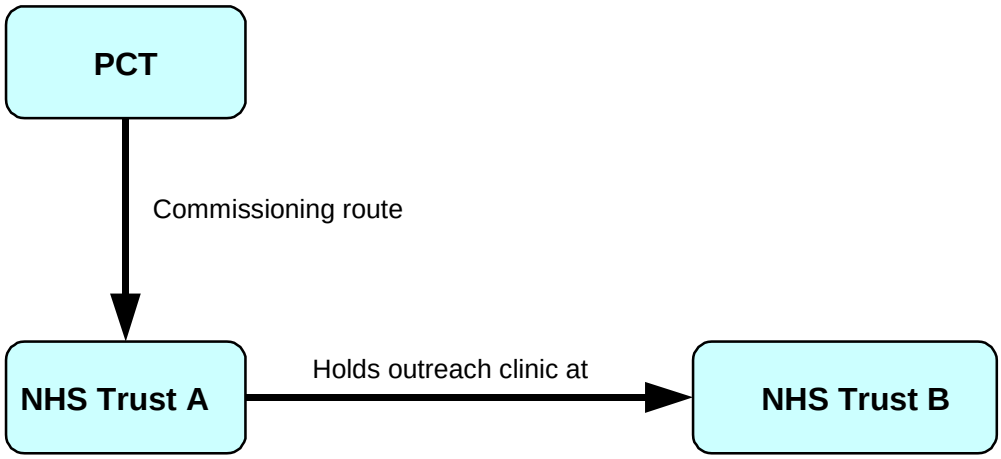
Scenario 1



In this scenario the patient is treated in an NHS Trust where this care is commissioned by a PCT (referred direct to a unit or centre). The patient will receive treatment/outpatient episode under the care of a consultant who has a contract to provide session(s) at this trust.

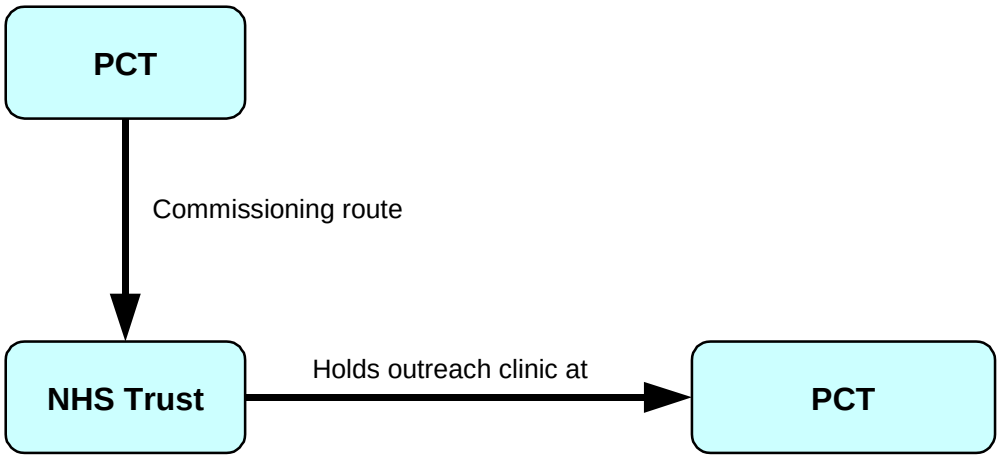
The activity and waiting time are recorded on the CWT-Db under the site code of the trust commissioned to provide the care.

Scenario 2



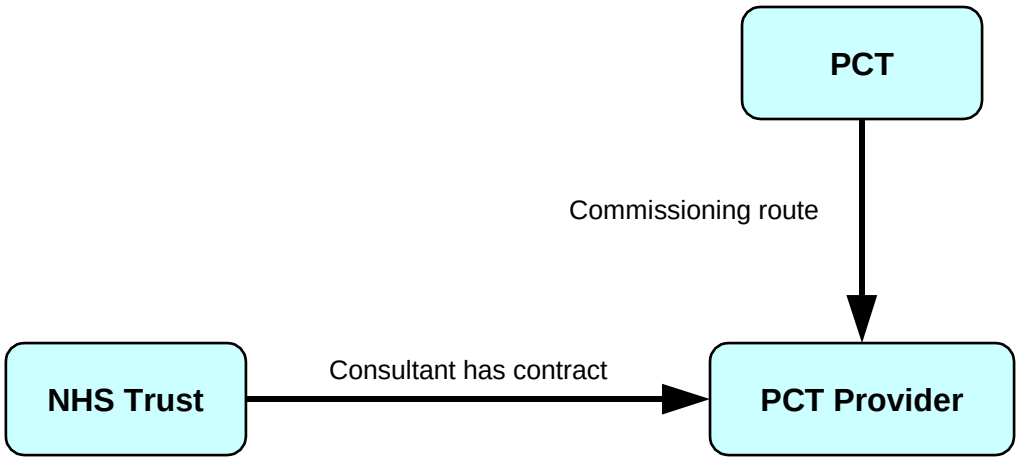
In this scenario the patient is seen in an outreach clinic at trust B, though the activity was commissioned from trust A by the responsible PCT. The activity is to be recorded on the CWT-Db under the site code of the trust that is commissioned to provide the service. This can be entered onto the CWT-Db as the site code of the trust headquarters.

Scenario 3



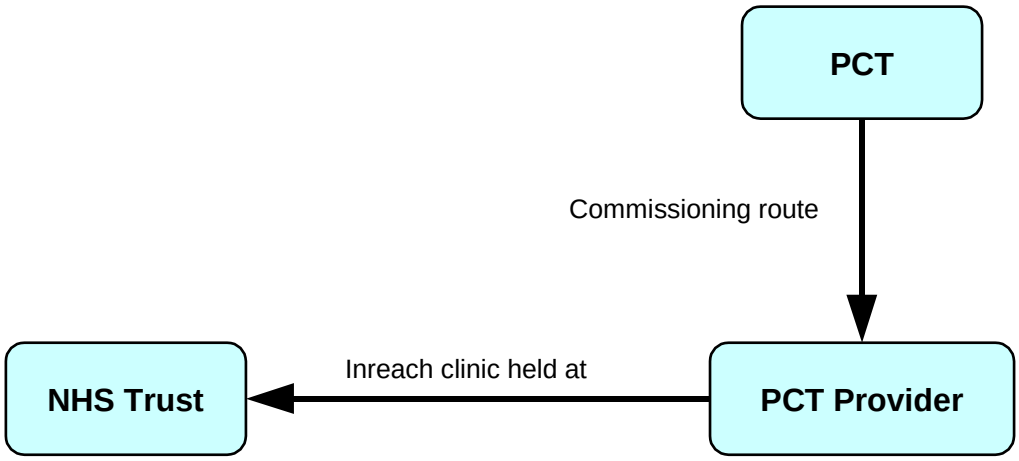
As above but the outreach clinic is at a PCT. Activity is recorded under the NHS Trust.

Scenario 4



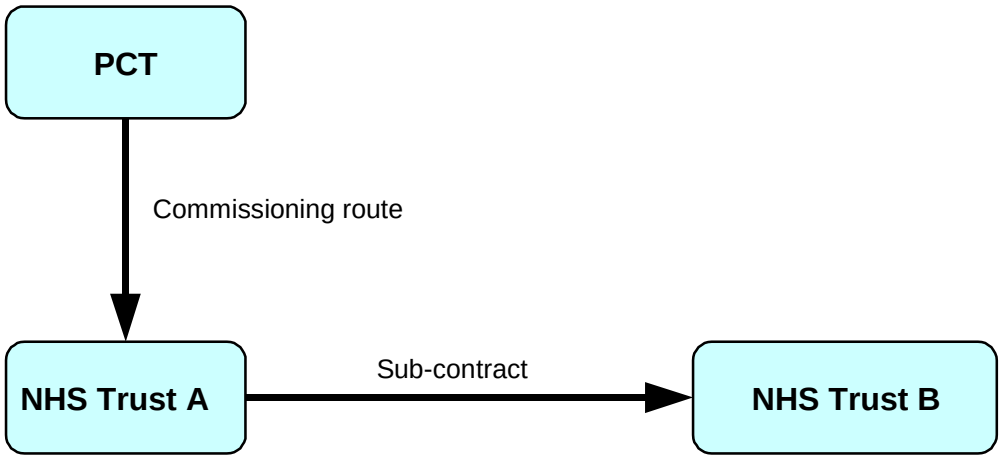
In this scenario the consultant may be based at the NHS Trust, but also has a contract of employment (to provide sessions) at the PCT. The PCT has been commissioned to provide the activity by itself or another PCT. The waiting time and activity are to be recorded on the CWT-Db under PCT provider site code.

Scenario 5



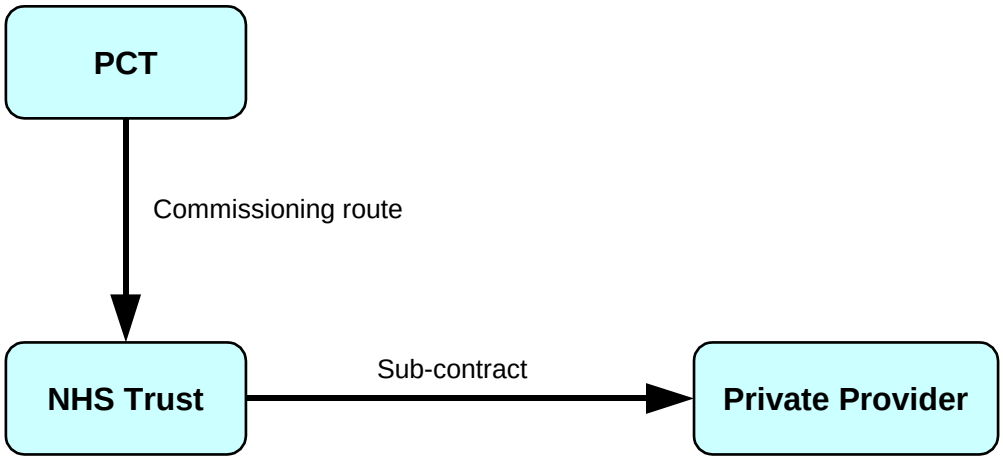
This scenario is the exact opposite of the outreach clinic. The PCT has had space made available to its staff in the local NHS Trust to provide the services it has been commissioned to provide. The activity is to be recorded on the CWT-Db under the site code of the PCT that is commissioned to provide the service. This is because the staff providing the clinical service are employed for the work by the PCT which is the commissioned provider.

Scenario 6



If the Trust A subcontracts the activity to a second NHS Trust (B) the activity is to be recorded on the CWT-Db by the trust that was originally commissioned to provide the work. This activity is to be recorded under the site code of the administrative headquarters of this NHS Trust A.

Scenario 7



This scenario is similar to scenario 6. The trust has taken out a sub-contract with a private provider. This activity is to be treated as if it was carried out by an NHS provider. This activity is to be recorded on the CWT-Db as if it was carried out at the trust that was originally commissioned to provide the work. This activity is to be recorded under the site code of the administrative headquarters of this NHS Trust.

Part 2 - Which patients do the targets apply to?

2.1 Do the targets include patients who are not referred through the urgent GP (two week wait) route?

The 31 day target applies to all new diagnoses of cancer regardless of the route of referral. For example this will include urgent GP referrals, routine GP referrals and screening referrals.

The 62 day target only applies to patients who are referred through the two week wait referral route. However this applies to ALL patients referred through this route, irrespective of whether the referral was received within 24 hours.

2.2 Which patients should be included in the monitoring?

The NHS Cancer Plan standards have been set for all patients cared for under the NHS in England and these patients should be monitored.

If the NHS commissions a private provider to undertake cancer care then this is still NHS activity and should be reported against cancer waits targets. If the care of a patient is sub-contracted (and hence paid for) by an English NHS Trust then this patient should be recorded under this NHS Trust.

In the case where a patient chooses to be seen initially by the specialist privately but is then referred for first definitive treatment under the NHS, the patient should be included under the 31 day decision to treat to treatment target.

Some patients are first seen under the Two Week Wait in the NHS, but may then choose to have diagnostic tests privately before returning to the NHS for cancer treatment. As part of the pathway was outside the NHS the patient should be recorded against the two week standard and 31 day standard only.

The majority of first treatments will be provided in secondary or tertiary care. If first definitive treatment is provided by a PCT provider this should be recorded on the CWT-db. The PCT will need to be set up as a provider on the CWT-db, to enable data to be uploaded by them. This needs to be done through the helpdesk, contact number 01392 251 289.

2.3 Do the treatment targets apply to patients receiving treatment for recurrence of cancer?

The targets only apply to patients with a newly diagnosed cancer. Some patients have metastases at presentation and so the treatment may be to the metastatic site rather than the primary site.

The targets do not apply to a patient receiving treatment for a recurrence of cancer. Clearly good clinical practice involves treating patients with recurrence as soon as possible on the basis of clinical priority.

When a patient is diagnosed with a second new cancer, which is not a recurrence, then the targets will apply to the treatment of this cancer (see part 6 for further details).

2.4 Do the treatment targets apply to patients who decline treatment?

Patients who decline any treatment should be excluded from the monitoring. However, even if there is no anti cancer treatment almost all patients will be offered a palliative intervention (e.g. stenting) or palliative care (e.g. symptom control) and these patients should be monitored.

2.5 Do the treatment targets apply to patients who die before treatment commences?
The targets concern waiting time to treatment. Hence patients who die before treatment commences should be excluded from the monitoring.

2.6 Are there any cases when the treatment time will exceed the target time?
In a small number of cases there will be good clinical reasons for treatment time exceeding the target time. A generic example of this is where a patient is referred under the two week wait and there is diagnostic uncertainty as to whether they have cancer or not. These patients may require repeat diagnostic tests in order to reach a diagnosis.

- A patient who requires a particularly complex combination of scans and biopsies
- A patient for whom there is genuine clinical uncertainty about the diagnosis and the clinician elects to observe the patient over (say) a three-month period.

These patients will exceed the 62 day wait and this should be recorded on the cancer waits system. Detailed reasons on why these patients exceeded the target time should be recorded on the CWT-db. It will not be appropriate to make adjustments in these cases. The Healthcare Commission will be publishing details of the thresholds to be allowed to take account of these clinical exceptions.

2.7 How do we monitor the following patient pathway? A patient is referred with a small breast lump which is fully assessed (e.g. by triple assessment, examination, imaging and needle biopsy) and is thought to be benign. The patient is reassured that the risk of this being cancer is low, but the clinician wants to check progress in 3 months. At that time it is clear that the lump is larger and a repeat biopsy shows cancer.

From the patient's perspective the interval between referral and diagnosis is clearly greater than 3 months. The waiting time reported should reflect this. We have always recognised that a small number of patients will breach for clinical reasons and this would be such a case.

2.8 At what point does a two week wait patient cease to be tracked as a potential 62 day wait patient?

A two week wait patient will cease to be tracked if a formal 'non-malignant' diagnosis is made (e.g. COPD). The patient comes off the 62 day monitoring. If the patient is subsequently diagnosed with cancer, they will enter the 31 day pathway from the date of decision to treat. This will include patients that are diagnosed with in-situ disease as these patients are not included in the cancer waits targets (except DCIS in breast care).

Where a two week wait patient is followed up due to diagnostic uncertainty, the patient remains on '62 day tracking', but will become a clinical exception as and when cancer is diagnosed, if they are treated outside the 62 days (see 2.6 above).

2.9 Does the 62 day target apply when a patient is referred on suspicion of one cancer but is diagnosed with a different cancer?

Yes, any patient who is referred as a suspected cancer and diagnosed with cancer should be monitored under the 62-day target from urgent referral to treatment. To meet this target trusts will require rapid handover arrangements between tumour groups where this situation can arise. Examples of the tumour groups where this may occur include:
* Gynae/Colorectal (symptoms non-specific)
* Breast/Lymphoma (axillary lumps)

* Head and Neck/Lymphoma/Lung (neck lumps)
* Upper GI/Lower GI (symptoms non-specific)

Part 3 - How are the waiting times calculated in the national database?

(The table below refers to data items which are fully explained in DSCN 22/2002. Database field names are in capitals)

3.1 Reports: The national database will provide reports for each of the waiting times targets. The table below specifies how the database will select records for a report and how the waiting time for each patient is calculated. *For the reporting period starting x and ending y*

For Target	Database will select records where	Calculation of waiting time:
Urgent GP referral to date first seen	DATE FIRST SEEN is between x and y **and** SOURCE OF REFERRAL FOR OUTPATIENTS = 03 or 92 **and** CANCER REFERRAL PRIORITY TYPE = 01	DATE FIRST SEEN **minus** CANCER REFERRAL DECISION DATE **minus** WAITING TIME ADJUSTMENT (FIRST SEEN)
Urgent GP referral to date of first definitive treatment	START DATE (first treatment) is between x and y **and** SOURCE OF REFERRAL FOR OUTPATIENTS = 03 or 92 **and** CANCER REFERRAL PRIORITY TYPE = 01 **and** PRIMARY DIAGNOSIS (ICD) is cancer[+]	START DATE (first treatment) **minus** CANCER REFERRAL DECISION DATE **minus** the sum of ▪ WAITING TIME ADJUSTMENT (FIRST SEEN) ▪ WAITING TIME ADJUSTMENT (DECISION TO TREAT) ▪ WAITING TIME ADJUSTMENT (TREATMENT)
Decision to treat to first definitive treatment	START DATE (first treatment) is between x and y **and** PRIMARY DIAGNOSIS (ICD) is cancer[+]	START DATE (first treatment) **minus** DECISION TO TREAT DATE **minus** WAITING TIME ADJUSTMENT (TREATMENT)

[+] See appendix D of DSCN 22/2002 for full details

3.2 Data Download:
In addition to reports against the waiting times targets the database will allow authorised users within Trusts and CSC teams, to download **all** data held within the database on any patient seen or treated within the Trust. This data will be patient level. For a full listing of the data items which can be recorded on the database see DSCN 22/2002.

3.3 For monitoring purposes, how many days is one month?

A month is taken to be 31 calendar days. Two months is 62 calendar days. Two weeks is 14 calendar days.

3.4 How do we count the days waited?

The date at the beginning of the waiting period is day 0. Hence is order to meet the 14 day standard if a patient is referred on 1st February the patient would need to be seen on or before 15th February.

Part 4 - FIRST DEFINITIVE TREATMENT

4.1 Several questions have been raised by Trusts regarding both the definition of "first definitive treatment" and the date which should be recorded. These issues have been considered by the Cancer Waiting Times Implementation group and the National Cancer Director. Guidance is given in the following paragraphs:

4.2 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 "first definitive treatment" and the start date are usually straightforward.

- A second group of 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 "first definitive treatment" is the first of these modalities to be delivered, and the date is the start date of this first treatment.

- A third group of patients 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. Such interventions might include formation of a colostomy for an obstructed bowel or insertion of an oesophageal stent. 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.

- A fourth group of patients undergo a clearly defined palliative intervention (e.g. a colostomy or a stent) but do 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.

- A fifth group of patients do 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 "treatment". This will include patients who are referred for possible anti-cancer treatment, but are found to be unsuitable and so receive specialist palliative care only.

- A sixth group 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 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". It is recognised that this is somewhat unsatisfactory as this group encompasses patients with early cancer (e.g. localised prostate cancer where serial monitoring of PSA is undertaken) and those with advanced cancers for which no immediate specific interventions are considered to be warranted. These patients may, of course, require general palliative care including symptom control – given under the care of GPs and/or oncologists. [NB At a later date revisions to the dataset will be considered but these cannot be made immediately]

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

First definitive treatment type	**Circumstances where this applies**
Surgery	♦ Complete excision of a tumour ♦ Partial excision/debulking of a tumour (but not just a biopsy for diagnostic or staging purposes) ♦ Palliative interventions (e.g. formation of a colostomy for a patient with an obstructing bowel cancer, insertion of an oesophageal stent or pleurodesis)
Drug treatment: Chemotherapy, *Biological therapy*[+] OR Hormone therapy	♦ Chemotherapy (including cases where this is being given prior to planned surgery or radiotherapy)
	♦ Biological therapy includes treatments targeted against a specific molecular abnormality in the cancer cell (e.g. rituximab, trastusumab, glivec) and treatments which target the immune system (e.g. interferon, interleukin 2, BCG).
	♦ Hormone Treatments should count as first definitive treatment in two circumstances (1) Where hormone treatment is being given as the sole treatment modality (2) Where the treatment plan specifies that a second treatment modality should only be given after a planned interval. This may for example be the case in patients with locally advanced breast or prostate cancer where hormone therapy is given for a planned period with the aim of shrinking the tumour before the patient receives surgery or radiotherapy.
Radiotherapy	♦ Given either to the primary site or to treat metastatic disease. This should include cases where radiotherapy is being given prior to planned surgery or chemotherapy.
Specialist Palliative Care (SPC)	♦ Given via hospital SPC teams ♦ Given via community SPC teams ♦ (Given via hospices – please note this cannot be recorded on the CWT-db as this only records care given by trusts)
Active monitoring	♦ When none of the other defined treatment types apply and the patient is receiving symptomatic support and is being monitored. The date of commencement of active monitoring should be the consultation date on which this plan of care is agreed with the patient, including the intervals between assessments (e.g. serial PSA measurements for prostate patients). This treatment type may be used for any tumour site if appropriate. ♦ For the purposes of waiting times the field active monitoring should also be used to record patients with advanced cancer who require general palliative care.

[+]Biological therapy – For the purposes of the national database Biological Therapy should be recorded as "chemotherapy" in the field PLANNED CANCER TREATMENT TYPE as defined in DSCN 22/2002.

4.4 What is the date of treatment where treatment is self-administered?
The Start date of treatment is taken to be the date of the outpatient appointment where the patient is given the prescription.

4.5 Where should palliative procedures such as stenting be recorded?
To be consistent with the Cancer Dataset any procedure should be recorded under surgery. Section 7 of the cancer dataset is designed to collect all surgery and all other procedures and hence a palliative procedure such as stenting should be recorded under surgery.
Of course the waiting dataset will not tell us whether the surgery is curative, palliative or what the intervention is. Trusts and networks may want to record the intention of the surgery or the OPCS 4 code of the procedure, but that is beyond what is required nationally to monitor waiting times.

4.6 How should we record supportive care drugs on the database?
Where a patient receives palliative care only they may of course be treated with supportive care drugs, but this is not recorded as first treatment. The first treatment should be recorded as one of the following:

i. Where the patient does not receive any anticancer treatments but is 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 "treatment".

ii. Where the patient is not referred to an SPC team and is receiving symptomatic support and is being monitored these patients should be classified as undergoing "Active Monitoring".

4.7 How should a patient who is diagnosed incidentally for cancer be monitored?

Some patients may be diagnosed for cancer during routine investigations or while being treated for another condition. This is why we have set targets from decision to treat to treatment, and once cancer is diagnosed the patient should be treated without delay. These patients should be monitored under the 31 day decision to treat to treatment target. Where the patient is treated immediately at point of diagnosis the decision to treat will be the same date as the date of the operation. (e.g. when a patient is unexpectedly found to have a cancer during surgery for a suspected benign condition).

4.8 Can a diagnostic procedure also be counted as treatment?
A purely diagnostic procedure (including biopsies) does not count as treatment unless the tumour is effectively removed by the procedure, examples of this would be a polypectomy during a colonoscopy or an excision biopsy of a melanoma. If the excision biopsy is therapeutic in intent (i.e. the intention is to remove the tumour) then clearly this will count as first treatment, irrespective of whether the margins were clear.

4.10 – How are patients who are treated for cancer under a clinical trial monitored?
The cancer waits standards apply to all patients treated under the NHS and so has to include patients treated under clinical trials. A suspension does not apply simply because a patient is participating in a clinical trial.

4.11 Are Carcinoid tumours reported for cancer waits?
Carcinoids of the appendix are coded as D37.3 and so are not reported for cancer waits, but carcinoids of any other site are coded to a C code in ICD10 and so are reported for cancer waits.

Haematology

4.12 If a patient has a blood transfusion would this count as first treatment?
If a patient is not planned to have active anticancer treatment (e.g. chemotherapy or radiotherapy) then a blood transfusion should count - as a palliative care treatment (e.g. for chronic lymphocyte leukaemia).
In all other circumstances the blood transfusion would not count as first treatment.

4.13 Would anti-biotics be counted as first treatment for low grade gastric lymphomas?
Yes anti-biotics would count as start of treatment for low grade gastric lymphoma.

4.14 What counts as treatment for lymphoma?
The removal of a lymph node is a biopsy to establish diagnosis and would not count as start of treatment as there is disease throughout the body. Patients will be treated with chemotherapy, radiotherapy or observation depending on the biopsy diagnosis.

Breast

4.15 In the treatment of breast cancer what is the position when a patient has immediate reconstruction as part of the first definitive treatment?
When a patient has immediate reconstruction as part of the first definitive treatment this should be within a month of decision to treat where this can possibly be achieved. However if a patient is offered alternative definitive treatment within a month, i.e. Mastectomy without immediate reconstruction, but instead chooses to have the immediate reconstruction at a somewhat later date, the provider should not be penalised for this. Full details on these patients should be provided by the trust in the exception report. These patients were removed from trust figures centrally prior to Healthcare Commission ratings assessment for 2004/5. From the end of 2005, these cases are treated as clinical exceptions. The HCC will publish how clinical exceptions across all tumour sites will be managed, and the thresholds which will take these into account.

4.16 Does Sentinel Node Biopsy count as start of treatment in breast cancer?
This does not count as start of treatment as this is a diagnostic procedure to determine whether cancer has spread to the lymph nodes.

Lung

4.17 Would "open and close" lung surgery count?
A small number of patients will undergo open and close surgery on the lung, which does not resect the lung. Although this does not remove the tumour this should still be counted as it is a treatment procedure, although the outcome is unsuccessful.

4.18 In lung cancer would the drainage of a pleural effusion count as treatment?
If a patient is not planned to have active anticancer treatment (e.g. chemotherapy) then this should count - as a palliative care treatment
In other circumstances it will not count.

4.19 In lung cancer would a mediastinoscopy count as first treatment?
No, this would not count as start of treatment

4.20 If a patient has a non small cell lung cancer and has to be stented can this be classed as a first treatment?
Yes this would be recorded as the start of cancer treatment.

Head and Neck

4.21 Would dental clearance count as start of treatment in oral cancer?
No, this would not count as start of treatment. An adjustment to the waiting time can be made if the dental clearance means the patient is unfit for radiotherapy and so the radiotherapy treatment is delayed (see section 8.10). The radiotherapy should be delayed by no more than 3 or 4 weeks due to dental extraction.

4.22 Head & neck patients often require the insertion of a PEG (Percutaneous Endoscopic Gastrostomy) prior to surgery or radiotherapy, would this count as the start of a first treatment?
The insertion of the PEG is not regarded as the start of treatment. If a patient requires nutrition via a PEG to make them fit for active treatment a medical suspension may be recorded.

4.23 Would a hemi-thyroidectomy count as start of treatment in patients diagnosed with Thyroid cancer?
Yes, hemi-thyroidectomy is considered as start of treatment.

Urology

4.24 How do we monitor patients with bladder cancer?

Cancer registries do not record carcinoma in situ or pTa transitional cell carcinoma as 'cancer' as they are regarded as non invasive. Patients with these histological diagnoses are therefore not counted for the purposes of the 31 and 62 day targets. (Grade 3 pTa are registered in ICD10 as in-situ tumours (D09.0) and grade 1 and 2 as borderline (D41.4))

For bladder cancer diagnoses, the TURBT counts as the first definitive treatment provided it is carried out with the intention of debulking rather than just carrying out a biopsy of the cancer. TURBT remains the first definitive treatment even for patients who require further treatment such as cystectomy or radiotherapy.

A TUR biopsy of a bladder cancer or a biopsy of metastatic disease will not count as first definitive treatment.

If a patient has completed the standard investigations for haematuria (i.e. normal cystoscopy and normal upper tract imaging) and no malignancy has been identified then a 'benign' diagnosis can be made and these patients will not be included in the 62 day target. However if monitoring or further tests are planned (e.g. because of abnormal urine cytology or equivocal upper tract imaging) then monitoring for the 62 day target cannot be stopped until these are complete and a benign cause is diagnosed.

4.25 What counts as first definitive treatment for Upper Tract Transitional Cell Carcinoma (TCC)?

First definitive treatments include:-

- Radical surgery (e.g. nephroureterectomy)
- Local excision (open or endoscopic)
- Chemotherapy
- Palliative therapy
- Surveillance

4.26 How do we monitor patients with prostate cancer?

Patients with a raised PSA or clinically suspected prostate cancer who are referred via the 2 week wait will continue to be monitored until cancer is diagnosed and the first definitive treatment commenced or an unequivocal benign diagnosis is made.

In practice there still remain some unclear areas.
If a patient has a raised PSA and the prostate biopsy shows benign tissue or PIN only, provided no immediate re-biopsy is planned then monitoring ceases. However if the suspicion of cancer remains (e.g. a very high PSA, suspicious histology or inadequate tissue obtained at the first biopsy) and a further immediate biopsy is planned despite the benign first biopsy the patient continues to be monitored.
Once a patient has been told that the diagnosis is benign even if continued assessment of the PSA is recommended, the patient is no longer tracked as a potential 62 day patient whether they are discharged or not.

For patients who have locally advanced or metastatic disease, first definitive treatment will usually be hormone therapy or watchful waiting.

For patients who apparently have localised disease and are suitable for curative treatment a pelvic MR scan may be indicated (see para 8.10 for guidance on stopping the clock).

Once a patient is given a number of treatment options, they may ask for time to think before selecting their preference. The clock stops while the clinician is waiting for the patient to decide (this is generally regarded as good practice). However the clock continues while the patient is waiting to see various specialists to discuss the different options e.g. surgeon, radiotherapist or brachytherapist.

First definitive treatment options include:-

- Radical surgery
- Radical radiotherapy
- Definitive treatment with new technology
- For those patients who have neo-adjuvant hormone therapy, the date of starting hormone therapy is taken as the first definitive treatment.
- Active monitoring
- Watchful waiting

If these options are chosen it is important to note the decision date clearly in the patient's case sheets for the monitoring team.

4.27 In prostate cancer would a TURP count as first treatment?
The guidance has been reviewed after further advice from urologists.
A TURP may be performed on known prostate cancer patients to palliate symptoms (where it could be regarded as de-bulking surgery).
In other patients a TURP may be carried out for benign disease and incidentally diagnose and treat prostate cancer.
In both cases this will count a start of treatment.

4.28 How do we track a two week wait patient who refuses altogether to have a TRUS biopsy but the clinician continues to review?
The TRUS biopsy will potentially diagnose the patient and by refusing altogether to have a TRUS the patient has removed themselves from the 62 day pathway. If cancer is subsequently diagnosed then the patient will be monitored under the 31 day target.

Where a patient delays a TRUS biopsy an adjustment should be made, and tracking as a potential 62 day patient should continue.

4.29 What counts as first definitive treatment for kidney cancer?

First definitive treatments include;-

- Surveillance
- Radical surgery
- Local excision (nephron sparing surgery)
- Ablation using new technology
- Immunotherapy
- Palliative care

4.30 What counts as first definitive treatment for testis cancer?

First definitive treatments include

- Orchidectomy
- Chemotherapy
- Palliative care

4.31 What counts as first definitive treatment for penile cancer?

First definitive treatments include

- Debulking operation e.g. circumcision, excision biopsy
- Radical surgery e.g. amputation, excision inguinal lymph node metastases
- Radiotherapy
- Chemotherapy
- Palliative care

Carcinoma in situ is not classed as invasive and so is not included in cancer waiting times data

Gynaecological

4.32 What would count as the date of first treatment in Gynaecological Cancer?

- Date of admission for surgery (or date of admission as emergency if proceeds to surgery during that admission). A cone biopsy should count as first treatment in early cervical cancer as it is a curative / definitive treatment for stage 1a disease. A diagnostic loop biopsy in more advanced cases would not usually be called a "cone" biopsy.

- Open and Close surgery - Where a patient has a major laparotomy for (usually) ovarian cancer the intention is de-bulking (not diagnosis) and so will count as start of treatment.

- Date of first radiotherapy / chemotherapy where these are first treatments

- Date of first hormonal therapy where this is used as primary treatment (eg endometrial cancer in frail patients or very young patients with low grade disease)

- Date of “treatment enabling” intervention forming part of the planned “treatment package” (eg ureteric stenting for advanced cervical cancer)

- Date of palliative intervention (e.g. colostomy or stenting) where no specific anticancer therapy is planned

- Date of the first assessment by a member of the Specialist Palliative Care team for patients who do not receive any anticancer treatments. Diagnosis does not need to be confirmed by histology / cytology for inclusion into statistics.

- "Active Monitoring": for patients who receive symptomatic support but who do not receive any specific anticancer treatment / intervention and are not referred to a SPC team – rare in gynae oncology

4.33 How do we record the wait for a patient with ovarian cancer who requires the drainage of Ascites prior to being fit for chemotherapy?
In this situation a medical suspension would apply for the period the patient is medically unfit for the chemotherapy (see para 8.9 and 8.10 for further guidance).

Upper GI

4.34 Would the insertion of a pancreatic stent count as start of treatment for pancreatic cancer?
After discussions with national leads it has been agreed that the **previous guidance needs to be amended.**
If the planned first treatment is resection for pancreatic or related cancers (ampullary, duodenal and distal bile duct), but subsequently the patient requires a stent due to a delay to having the surgery then stenting will not count as start of treatment. Many clinicians agree that patients with mild obstructive jaundice (a serum bilirubin below 200 micromol/l) do not require bilary stenting before resection, if surgery and imaging are planned within 7-10 days. If this is the agreed clinical practice locally then stenting for these patients will not count as start of treatment.
If the planned first treatment is to insert a stent in order to resolve jaundice before the patient has a resection or the patient starts chemotherapy stenting will count as start of treatment.

4.35 Should gastrointestinal stromal tumours (GISTs) be recorded for cancer waits?
GISTs that are described as malignant, invasive or as having metastases are coded to the relevant C code for the part of GI tract involved and are thus included in the cancer waits. GISTs not otherwise specified are coded as borderline using the relevant D code and are not recorded for cancer waits.

4.36 Would a jejunostomy count as start of treatment?
The jejunostomy would not count as start of treatment as it is a procedure to insert a feeding tube. However if a patient is medically unfit while they recover from the procedure before start of treatment (e.g. chemotherapy) it is appropriate to make an adjustment and to suspend the patient for the period they are unfit.

Brain/CNS

4.37 When a patient with a Brain tumour is given Dexamethasone would this count as first treatment?
Dexamethasone will only count if the patient is only being cared for palliatively and no other anti-cancer treatment is offered.

4.38 Should treatment of Von Hippel-Lindau syndrome be recorded on cancer waits?
No, this is a benign condition and so is outside the monitoring of cancer waiting times.

4.39 Which grades of brain tumour do we report for cancer waiting times?
Grade 3 and 4 tumours are considered malignant and should be reported for cancer waits. Grade 1 and 2 tumours are benign and so should not be recorded for cancer waits.

Skin

4.40 In skin cancer are Intraepidermal carcinomas, Lentigo malignas or bowen's disease included in the monitoring of cancer waiting times targets to treatment?

No. All these conditions are classified as carcinoma in-situ of the skin and so are outside the scope of diagnoses monitored for cancer waiting times. Full details of the diagnosis codes covered in cancer waiting times are available in DSCN 22/2002.

Part 5 - What is the “FIRST DIAGNOSTIC TEST”?

5.1 This appendix provides a list of first major diagnostic tests. The first major diagnostic test is the test which will move the level of suspicion of cancer from "possible/probable" (based on history, clinical examination or blood count) to "highly probable/certain". This list is not exhaustive and so should be used as a guide to help teams in recording this data.

Primary tumour type	**First major diagnostic test likely to be one of the following**
Breast	Mammogram, Ultrasound, Needle Biopsy, Sentinel Node Biopsy
Lung	Bronchoscopy, CT scan or MRI
Colorectal	Barium Enema, Flexible Sigmoidoscopy, Rigid Sigmoidoscopy, Colonoscopy, biopsy, ultrasound for abdominal mass, CT, digital rectal exam, MRI
Upper GI	Barium Meal/Swallow or Gastroscopy
Urology	I.V.U., flexible cystoscopy, trans-rectal ultrasound. P.S.A., Ultrasound, TRUS biopsy
Gynaecology	OVARY: Ultrasound Scan or Ca 125(usually), CT scan (in some cases) CERVIX: Biopsy VULVA: Biopsy, Vulvoscopy ENDOMETRIUM: Vaginal Ultrasound, Endometrium Assessment/Sampling, Hysteroscopy
Haematology	Full Blood Count, Bone Marrow, Node Biopsy or CT scan, removal of a lymph node is a biopsy to establish diagnosis
Skin	Biopsy
Head and Neck	Upper airways endoscopy, biopsy, CT scan, MRI
Brain	CT or MRI scan

The date of the first diagnostic test is recorded in the field
CLINICAL INTERVENTION DATE (FIRST DIAGNOSTIC TEST)

The date of the first diagnostic test must be after the patient has been referred to secondary care(page 13, User Manual for further details)

Part 6 - When should a new record be created?

6.1 A new record is required for each new cancer care spell. This appendix provides definitions of a cancer care spell for breast, lung and skin cancers. The definitions of cancer care spells for other tumour types are being agreed through the development of the National Cancer Dataset and will be available in subsequent versions of the Dataset document (which will be made available on the Health and Social Care Information Centre website).

6.2 In general, recurrence of cancer at the same site is considered to be part of the same care spell (so it does not require a new record) but it would be the subject of a new care plan for its management. The treatment targets in the Cancer Plan only apply to first definitive treatment of newly diagnosed cancers.

6.3 Breast Cancer (see exceptions below)

A new Cancer Care Spell for breast cancer should be started for:

- different histology
- different laterality

So, simultaneous bilateral breast tumours with the same histology would result in two Cancer Care Spells, one for the right breast and one for the left breast.

Multi-focal tumours (i.e. discrete tumours apparently not in continuity with other primary cancers originating in the same site or tissue) would result in one Cancer Care Spell (unless they have different histology and/or different laterality).

6.4 Lung (see exceptions below)

A new Cancer Care Spell for lung cancer should be started for:

- Any tumour with a different histology, irrespective of ICD-10 code or laterality
- A tumour with a different three-character ICD-10 code, except in cases where this is considered to be recurrence of the original primary tumour
- A tumour with different laterality except in cases where this is considered to be recurrence of the original primary tumour

However, a single lesion of one histological type is considered a single primary (i.e. one Cancer Care Spell), even if the lesion crosses site boundaries above. Differences in histological type refer to differences in the first three digits of the morphology code.

So, simultaneous bilateral lung tumours with the same histology (excluding metastases) would result in two Cancer Care Spells, one for the right lung and one for the left lung.
Multi-focal tumours (i.e. discrete tumours apparently not in continuity with other primary cancers originating in the same site or tissue) would result in one Cancer Care Spell (unless they have different histology and/or different laterality) – unless these were considered to be metastatic from the primary tumour.

6.5 Skin Cancer
There are particular rules for recording skin cancers within the Cancer Dataset, which apply when collecting skin cancer data for monitoring of Cancer Waiting Times. For full details please see the Cancer Data Manual. **Please note that data on the treatment of basal cell carcinomas is not required for the cancer waiting system as they are not covered by the cancer waiting times targets to treatment(see DSCN 22/2002 for further details).**

For 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 spell (i.e. one record) should be recorded for all these Squamous Cell Carcinomas.

For Kaposi's sarcoma – A new cancer care spell should be started for each Kaposi sarcoma diagnosed.

Malignant Melanoma – A new cancer care spell should be started for each Malignant Melanoma diagnosed.

Cutaneous Lymphomas - A new cancer care spell should be started for each cutaneous lymphoma diagnosed.

6.6 Exceptions

The Cancer Waiting Times database works on the basis of a single dataset record for a given Cancer Referral Decision Date or a given Decision to Treat date. Hence there are rare occasions when the database cannot record both cancer care spells:

1. If a patient is referred by the GP for two different suspected cancers **on the same date,** only the first of these can be recorded.
2. If a patient is urgently referred for suspected cancer and is diagnosed with two separate cancers (which both relate to the **same Cancer Referral Decision Date**), only the cancer first treated can be recorded on this record. Where the decision to treat date for these cancers is different, treatment data for the second cancer should be recorded as a new record and information recorded from the date of decision to treat to date of first definitive treatment (start date).
3. If the decision to treat date **is the same date** for 2 separate cancers only the first of these cancers can recorded.

Part 7 – Data and the Database

7.1 What support is available for the database?

The user manual for the database is available at
http://nww.connectingforhealth.nhs.uk/nhais/cancerwaiting/documentation
For all enquiries on the database please call the Health and Social Care Information Centre helpdesk number **01392 251 289**.

7.2 How will non-mandatory data recorded on the database be used?

Mandatory data on the database are required to monitor the cancer plan targets. In addition the database supports collection of a small number of additional data items that the Cancer Services Collaborative have shown are useful to support service improvement. All non-mandatory data items will only be available for local use.

Section 10 of the user manual outlines exactly what information will be reported from the database. The user manual is available at
http://nww.connectingforhealth.nhs.uk/nhais/cancerwaiting/documentation

Only the trust(s) who manage the care of individual patients will be able to download patient identifiable information. Strategic Health Authorities, PCTs and Networks can access an anonymised download of patient level records.

7.3 Will trusts be able to update data on patients for which there is an existing record on the database?

Yes. The database allows records to be automatically updated through the CSV upload or through manual entry on screen. See Cancer Waiting Times User Manual for details.

7.4 For which patients can we record CANCER REFERRAL DECISION DATE?

This may only be recorded on the database for Urgent Referrals from GPs/GDPs for suspected cancer. The Cancer Referral Decision Date and NHS Number together form the unique record identifier within the database for these records (see para 7.9).

7.5 Which data items within the database are required to monitor the Cancer plan Targets?

The table on page 6/7 of DSCN 22/2002 shows which data items are required for monitoring the Cancer Plan Targets. The table splits up data required on the two week standard and treatment data, as patients may be treated in a different organisation to where they are first seen.

"**Trust where first seen if urgent GP referral for suspected cancer**" - The M's show the data required for ALL two week wait referrals to allow reporting against the two week standard. i.e. A trust reporting the two week wait must ensure all the M's are complete for each record. Other data is optional or not applicable.

"**Trust where patient receives first definitive treatment for cancer following a referral other than an urgent GP referral for cancer**" - The M's show the data required on all cancer patients who do not come through the two week rule for monitoring the one month diagnosis (decision to treat) to treatment target. The Trust who delivers the first definitive treatment must ensure this data is complete. Other data is optional or not applicable.

"**Trust where patient receives first definitive treatment for cancer following an urgent GP referral for suspected cancer**". The M's show the data required on all cancer patients who come through the two week rule to enable monitoring of the one month diagnosis (decision to treat) to treatment target and the two months urgent referral to treatment target. The Trust who delivers the first definitive treatment must ensure this data is complete. These patients will already have the data from the first column recorded on them within the database. Other data is optional or not applicable.

7.6 Why are some of the options on SOURCE OF REFERRAL FOR OUTPATIENTS not available on the database?

The source of referral relates to the initial referral into secondary care and so should relate to the DATE FIRST SEEN. Some of the options are not available on the database in order to protect the integrity of this data (particularly for two week wait reporting) and to discourage trusts further down the pathway overwriting this data.

In some instances this field will be left blank. For example where a patient is initially seen in secondary care as an emergency admission this field should be left blank.

This data item is mandatory for two week wait patients only.

7.7 Which MDT discussion should be recorded on the database?

As stated in the NHS Cancer Plan, the care of all patients should be formally reviewed by a specialist team. This will be either through direct assessment or through formal discussion with the team by the responsible clinician. This will help ensure that all patients have the benefit of the range of expert advice needed for high quality care.

In line with the manual of cancer services, the date of MDT meeting in which the patient's treatment plan is agreed should be recorded on the database.

(Standard 2A-136 " The Core MDT, at their regular meetings should agree and record individual patient's treatment plans. A record is made of the treatment plan … including the multidisciplinary planning decision".)

7.8 How should the new codes for cancer status be used?

Cancer Status codes and descriptions

1	Suspected cancer
3	No new cancer diagnosis identified by the Trust
5	Diagnosis of new cancer confirmed – treatment not yet planned
6	Diagnosis of new cancer confirmed - NHS treatment planned
7	Diagnosis of new cancer confirmed - no NHS treatment planned
8	First treatment commenced (NHS only)

The purpose of item is to identify those urgent GP referrals for suspected cancer who require data to be recorded on first definitive treatment.

1 Suspected cancer

3 No new cancer diagnosis identified by the Trust
Use when benign or normal diagnosis or when a patient is diagnosed with a recurrence (see below).

5 Diagnosis of new cancer confirmed - treatment not yet planned
Use for patients with a new diagnosis of cancer, but where treatment is not yet planned.

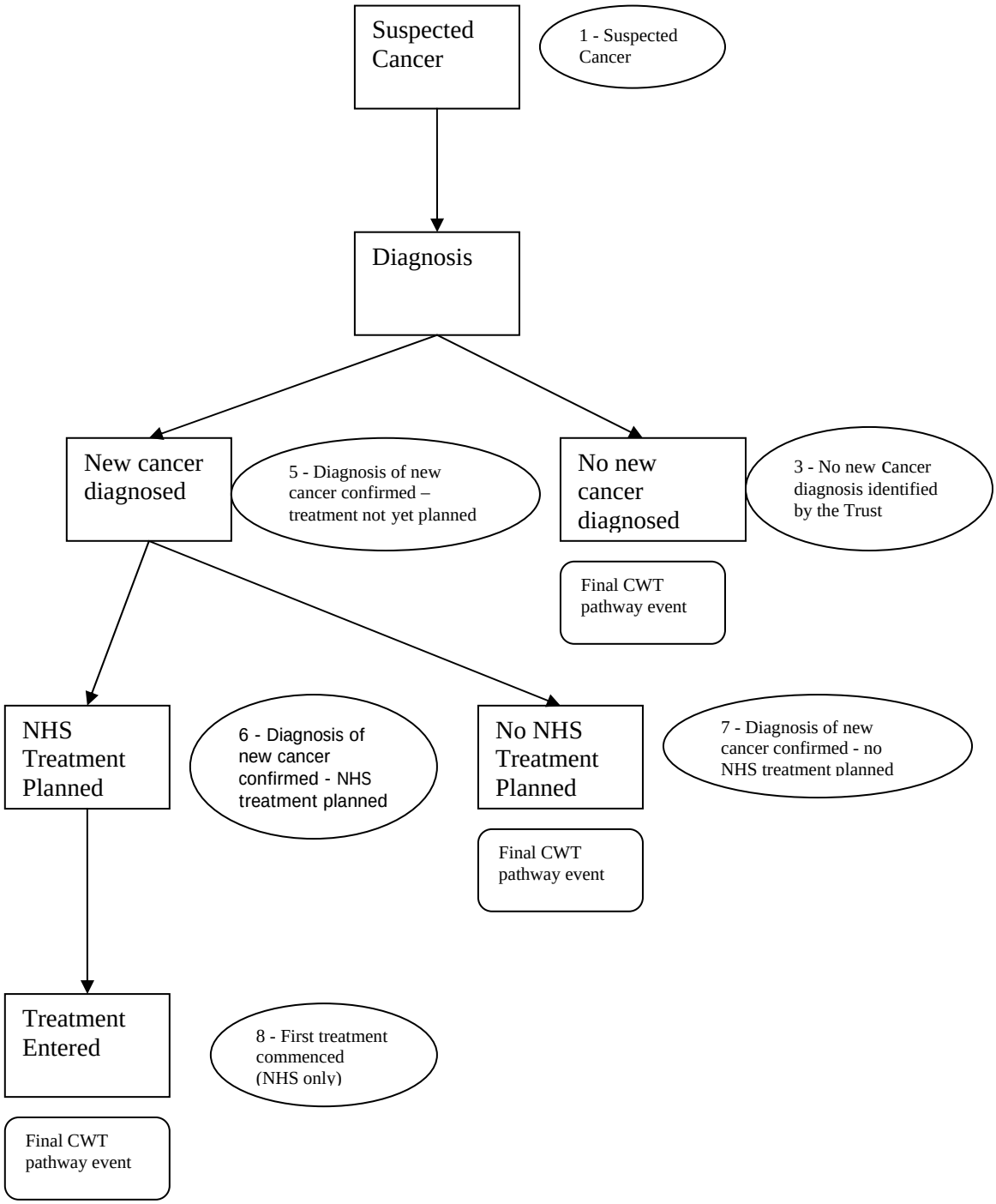
6 Diagnosis of new cancer confirmed - NHS treatment planned
Use for patients with a new diagnosis of cancer where NHS treatment is planned but has not yet commenced.

7 Diagnosis of new cancer confirmed - no NHS treatment planned
Use for patients with a new diagnosis of cancer where NHS treatment is not planned. Use this code when a patient dies before treatment, a patient refuses all treatment or a when a patient is first treated in an independent provider or the patient is first treated privately.

8 First treatment commenced (NHS only)
This code should be used when treatment under the NHS has commenced for a patient with a new diagnosis of cancer.

Patients diagnosed with a recurrence
The targets only apply to patients with a newly diagnosed cancer. Some patients have metastases at presentation and so the treatment may be to the metastatic site rather than the primary site.
The targets do not apply to a patient receiving treatment for a recurrence of cancer. Clearly good clinical practice involves treating patients with recurrence as soon as possible on the basis of clinical priority.
When a patient is diagnosed with a second new cancer, which is not a recurrence, then the targets will apply to the treatment of this cancer.

Cancer Status and the patient care pathway



7.9 How is the primary key for a record in the CWT-db defined?

(Option 1) NHS Number + "Cancer Referral Decision Date" - If the patient is referred as an Urgent GP/DP Referral for Suspected Cancer (Two week wait) Option 1 will be used and the trust where they are first seen has the responsibility to create the record on the system.

(Option 2) NHS Number + "Decision To Treat Date" - If the cancer patient is **NOT** an Urgent GP/DP referral for Suspected Cancer, Option 2 will be used and the trust where they are **treated** has the responsibility to create the record on the system.

To add further information to a two week wait record (I.e. treatment data) it is necessary to include the "Cancer Referral Decision Date" (and the NHS Number) in any subsequent upload records. This information ensures the database will identify the correct record.

This means that there needs to be local mechanisms in place to ensure that the "Cancer Referral Decision Date" is passed along the pathway if the patient crosses trust boundaries:

7.10 What data should be recorded on patient admitted as an emergency?

Some cancer patients are admitted as emergencies and remain as an inpatient until they receive their first treatment. When a patient receives surgery as the first treatment the START DATE(SURGERY) is defined to be the date of admission. In this example the DECISION TO TREAT DATE may be after the date of admission and hence the interval between decision to treat and start date is negative. These dates will be accepted by the database.

7.11 In what circumstances should we use the code "4 – patient choice" in the field WAITING TIME ADJUSTMENT REASON (FIRST SEEN)?

This code should only be used if a patient referred urgently by their GP as a suspected cancer makes it clear that they do not want an appointment within 14 days before an offer is made. The patient will be excluded from the reports generated on the CWT-db to monitor the Two Week Standard. However data on the patients waiting time should be uploaded onto the CWT-db, as this will be required for monitoring the Urgent Referral to treatment target if the patient is diagnosed with cancer.

Where a patient turns down an appointment offered within 14 days the code "2 – patient cancellation" should be used (for example the patient declines as they are on holiday on the date offered). The patient should be offered another appointment within 14 days of the cancelled appointment.

7.12 How do we record two week wait patients who are admitted as emergencies for the same condition before they are seen?

When a two week wait patient is admitted as an emergency for the same condition before they are seen they should not be counted under the two week rule. The emergency admission is the referral into the system and effectively supersedes the original referral.
Where a patient is admitted for another condition the original two week referral still stands.

7.13 How do we record new cases of cancer cases where there is no pathology available?

It is well recognised that some patients with cancer never have microscopic verification (i.e. histology or cytology). This is particularly the case for internal cancers such as pancreatic and for elderly patients with lung cancer who are deemed unfit for bronchoscopy. In these cases diagnosis is made on non-microscopic information such as radiological investigations. For practical purposes if a patient has been told they have cancer and/or have received treatment for cancer the relevant primary diagnosis code should be used.

7.14 How should we record ICD10 code on Chronic Lymphocytic Leukaemia?

Chronic Lymphocytic Leukaemia should be reported using the 3-digit code C91. The CWT-db requires all acute leukaemia's to four digits in order to identify these cases separately to monitor the 2001 treatment target, but in other cases of leukaemia the ICD10 code is only required to 3 digits.

Decision to Treat

7.15 Why is "decision to treat date" used to monitor the 31 day target?

Date of diagnosis is already well defined for cancer registration purposes. In some cancers it is common for the diagnosis to take place AFTER first treatment. For example in testicular cancer, orchidectomy is counted as the first definitive treatment, although definitive diagnosis will be obtained from this operation. The start date for monitoring this target should be one that is meaningful for patients. The decision to treat date is the date of the consultation in which the patient and clinician agree the treatment plan for first treatment. If the first treatment requires an admission (e.g. Surgery) this date is recorded on hospital PAS systems, as the "Date of decision to admit" (used for calculation of waiting list statistics). A decision to treat is dependent on the agreement of the patient and so may not be on the day of the MDT meeting.

7.16 What is the date of decision to treat for chemotherapy or radiotherapy?

Oncologists have agreed that the "decision to treat date" is the date the oncologist sees the patient and agrees that the patient is suitable for treatment and that the patient agrees the treatment plan.

7.17 Can a decision to treat be made with a patient prior to completing all staging tests?

Normally staging tests are completed prior to making a decision to treat. As stated above if first treatment requires an admission (e.g. Surgery) this date is recorded as "Date of Decision to admit" on hospital PAS systems and is used for measuring elective inpatient waiting times and should also be used for cancer waiting times.

7.18 What date is the decision to treat for brachytherapy in prostate cancer?

In order to determine whether the prostate is suitable for brachytherapy a volume study has to be performed. The date of the decision to treat will be the date of the consultation where the treatment is agreed after the volume study has been completed.

Part 8 – Guidance on Adjustments for Cancer Waiting Times

8.1 There is already guidance on recording waiting times for the purposes of calculating inpatient waiting list and waiting time central returns. (See: Mark Morrison letter of 13 August 2002 "Measuring and Recording Waiting Times")

8.2 This existing guidance also applies to the recording of waiting times in the cancer waiting times database. This note provides some specific examples of adjustments in the cancer pathway.

8.3 In line with current guidance on waiting times an adjustment to the waiting time of a patient is applicable in the following circumstances.

- Patient cancelled an outpatient appointment
- Patient Did Not Attend (DNA) an outpatient appointment
- Patient defers an admission
- Suspension for patient reasons (often referred to as social suspension)
- Suspension for medical reasons

8.4 Patient cancelled an outpatient appointment

- If this is the first outpatient appointment the clock restarts from the date of the appointment the patient was offered but refused. The adjustment is the number of days from date of decision to refer to date of appointment the patient refuses. (i.e. clock is reset)
- If this is a follow-up appointment the adjustment is calculated as the number of days from the date the patient was last seen to the date of appointment the patient refuses.

Note: If the provider cancels the appointment then there is no affect on the waiting time.

8.5 Patient Did Not Attend (DNA) an outpatient appointment

- If this is the first outpatient appointment the clock restarts from the date of the appointment the patient did not attend. The adjustment is the number of days from date of decision to refer to date of DNA. (i.e. clock is reset)
- If this is a follow-up appointment the adjustment is calculated as the number of days from the date the patient was last seen to the date of appointment the patient did not attend.

8.6 Patient defers admission

- Patient is offered a reasonable date for admission but refuses. Provided the admission date was a reasonable one (i.e. there was a sufficient amount of notice and the provider took account of personal circumstances) this is described as a self-deferral. In such a case the waiting time is adjusted by the number of days from date of decision to treat to the date the admission was scheduled to take place.

Example

- A patient is contacted by the trust and offered an admission date for surgery to treat their breast cancer. At this time they declare that they are unable to attend on this date as they have booked a holiday. This is a patient deferral. In this case the period between the admission date they declined and the decision to treat date is to be removed by an adjustment.

Note: if the provider cancels the admission then there is no affect on the waiting time. (e.g. the 31 day target waiting times is calculated from the original decision to treat date)

8.7 Suspension for patient reasons (often referred as social suspensions)

The clock stops when

- 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)
- When a patient requests a second opinion before making a decision on treatment. (The clock does not stop if the clinician requires a second opinion)
- **Suspensions must be clearly recorded in the patient notes**
- **The position of any patient suspended must be reviewed regularly.**

The clock does not stop

- When a patient chooses a treatment with a longer waiting time (e.g. radiotherapy rather than surgery)
- A patient should not be suspended 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.

8.8 Examples of social suspensions

- A patient with cancer is seen by the oncologist and is suitable for a clinical trial. The patient is given the details and told he/she needs to make a choice about whether or not they wish to take part in the trial. This two-step process is good practice in terms of informed consent. Whilst taking the time to make the decision, the patient will be classed as suspended for patient reasons as he/she is technically unavailable for treatment. The clock starts again as soon as the patient has told the oncologist of their decision.

Note: Allowing patients time to consider treatment options is part of good clinical practice and is not confined to clinical trials.

- A young 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 trust this can be

classified as a suspension for patient reasons. The period which the patient has made themselves unavailable should be adjusted out of the calculated waiting time.

8.9 Suspension for medical reasons

The clock stops when

- When a patient is unavailable for admission for a period of time due to another medical condition that needs to be resolved
- 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. reduce weight)
- **Suspensions must be clearly recorded in the patient notes**
- **The position of any patient suspended must be reviewed regularly.**

The clock does not stop

- When the trust 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.
- In patients for whom there is genuine clinical uncertainty about the diagnosis and the clinician elects to observe the patient over (say) a three month period.
- A patient should not be suspended 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

8.10 Examples of suspension for medical reasons

- 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 clock will only stop if the cardiology opinion is that the patient is medically unfit for cancer treatment. If the opinion is that the patient is fit for cancer treatment then the clock does not stop. Hence the clock does not stop whilst an opinion on the co-morbidity is being sought. A similar example would be where a patient with mouth cancer requires dental extraction prior to commencement of radiotherapy treatment – the clock would stop while the patient was not fit for treatment following the extraction, but not whilst they were waiting for the extraction.

- Patients with severe frailty/cachexia related to the cancer. A patient who requires intensive nutritional support (e.g. through intravenous feeding or through nasogastric feeding) before they are fit for surgery. The clock stops for the period the patient is medically unfit for surgery, with the start date of this period of suspension being defined as the date when a medical opinion as to their being unfit for treatment was received.

- A patient with cancer also has COPD. He/she is technically suitable for surgical resection but considered in need of a medical opinion (in this case usually a respiratory physician). The respiratory physician confirms the patient is medically unfit for the surgery at that time (clock stops at this point) (see above) and wishes to institute a changed therapeutic regime to optimise their respiratory function before surgery. The patient is suspended until medically fit for the surgery.

- In prostate cancer following a transrectal ultrasound-guided biopsy there may be swelling of the prostate gland. This makes interpretation of MRI scans unreliable. Many clinicians would advocate that there should be a planned interval of up to 4 weeks between biopsy and MRI, as the gland swelling means the patient is medically unfit for the scan and so a medical suspension is appropriate. Where this is agreed in local

clinical protocols and if the clinician agrees this with the patient, then an adjustment can be made to the waiting time for the period that the patient is unfit to progress to the scan (i.e. where the MRI is requested after biopsy the clock can be stopped from date of MRI request until the date that is a maximum of 4 weeks after the biopsy). The patient notes need to make it clear that a medical suspension was necessary. Of course this must not be used to mask delays to MRI scans or subsequent delays to surgery.

- In the absence of conclusive research regarding the optimum time interval from TRUS biopsy to radical prostate surgery, it has been agreed through clinical consensus that there could be a period of up to six weeks, depending on clinical judgement, between TRUS biopsy and radical prostate surgery. If this is agreed in local clinical protocols the patient should only be medically suspended for the period they are unfit (i.e. from the date it is agreed they will have radical surgery until the date 6 weeks after biopsy).

- If a cancer is found on barium enema a CT cannot be performed for up to 10 days as barium sulphate cannot be penetrated by X-Ray. A medical suspension may be recorded for the period the patient is unfit (following the decision that the patient requires a CT) if no other diagnostic activities can be carried out in this period and a CT scan was available within 10 days.

- Some patients diagnosed with primary liver cancer (Hepatoma) have an organ transplant as their first treatment. A patient should be suspended for the period that matched organs are not available.

8.11 Can we make an adjustment for radiographic investigations in menstruating females?
The Royal College issued guidance a few years ago indicating that, while the 28 day rule was satisfactory for most radiographic investigations, in menstruating females, the 10 day rule was safer for high dose investigations particularly barium enema and CT of the abdomen and pelvis (i.e. the procedure should be performed in the first 10 days of the menstrual cycle). Many departments also apply the 10 day rule for barium studies of the small bowel. Where this delays a patients investigation a medical suspension may be applied for the time the patient is unfit for the test.

8.12 How do we monitor a patient who agrees a treatment and then a week later changes their mind and wishes to receive a different treatment altogether?
The patient will have to agree a new decision to treat and hence the 31 day target clock is reset. For the 62 day target it is appropriate to remove the period from decision to treat to the date of cancellation and should be coded as a self-deferral.

8.13 How do we monitor a patient that refuses altogether the diagnostic test that may diagnose cancer but continues to be cared for by the trust?
In effect the patient, by refusing the diagnostic test, has taken them self off the 62 day pathway. The trust can not deliver on a patient who is not prepared to "be on the pathway". If the patient agrees at a later stage to have the test and is subsequently diagnosed with cancer, they should be monitored against the 31 day standard.

8.14 How do we monitor a patient that turns up for their diagnostic test but then refuses the test and has to be re-booked at a later date?
If the trust has done everything possible to avoid this happening (e.g. the patient is fully informed about what to expect) then the patient can be considered as having been self-deferred (or patient cancellation) and so an adjustment may be made.

8.15 How are adjustments to waiting times made?

There are three adjustment fields within the Cancer Waiting Times Database (CWT-Db) to record adjustment values depending on which point on the referral to treatment pathway the adjustment is appropriate.
WAITING TIMES ADJUSTMENT (FIRST SEEN) – To record adjustment (in days) between referral decision date and date first seen.
WAITING TIMES ADJUSTMENT (DECISION TO TREAT) – To record adjustment (in days) between date first seen and date of decision to treat.
WAITING TIMES ADJUSTMENT (TREATMENT) – To record adjustment (in days) between date of decision to treat and start date of treatment.

If an adjustment is recorded a user is also required to give the reason for adjustment (using the fields WAITING TIME ADJUSTMENT REASON (FIRST SEEN), WAITING TIME ADJUSTMENT REASON (DECISION TO TREAT), and WAITING TIME ADJUSTMENT REASON (TREATMENT)

Please Note: A comment in the delay reason comment field will **not** result in a patient's waiting time being adjusted. The system requires the adjustment fields above to be completed in order to calculate an adjusted waiting time.

8.16 Examples of adjusting a patients waiting time

Example A: The patient and surgeon agreed first definitive treatment of surgery on 01/11/2002. The date of admission for this surgery was 25/11/2002, but the patient defers treatment. The patient is then admitted on 09/12/2002 for the surgery.
DECISION TO TREAT DATE (SURGERY) = 01/11/2002
START DATE (SURGERY HOSPITAL PROVIDER SPELL) = 09/12/2002
WAITING TIME ADJUSTMENT (TREATMENT) = 25/11/2002 – 01/11/2002
= 24 days
The database will then calculate the waiting time for the decision to treat to treatment target which will be reported as 14 (START DATE (SURGERY HOSPITAL PROVIDER SPELL) - DECISION TO TREAT DATE (SURGERY) - WAITING TIME ADJUSTMENT (TREATMENT))

Example B: A GP decides to refer a patient under the two week standard on 03/02/2003 and the patient is given an appointment for 11/02/2003. The patient cancels this appointment and is given another appointment for 18/02/2003, which the patient attends.
CANCER REFERRAL DECISION DATE = 03/02/2003
DATE FIRST SEEN = 18/02/2003
WAITING TIME ADJUSTMENT (FIRST SEEN)
= 11/02/2003 – 03/02/2003 = 8 days
The database will calculate the waiting time from the above information and the reported waiting time will be 7 (DATE FIRST SEEN - CANCER REFERRAL DECISION DATE - WAITING TIME ADJUSTMENT (FIRST SEEN))

Example C: The patient above (who was first seen on 18/02/2003) cancels their follow-up appointment on 25/02/2003. The patient is given another appointment for 04/03/2003, which the patient attends. The consultant and patient agree the first definitive treatment of surgery on 11/03/2003.
Date Last Seen = 18/02/2003
WAITING TIMES ADJUSTMENT(DECISION TO TREAT)
= Cancelled follow-up appointment – Date last seen
= 25/02/2003 – 18/02/2003
= 7 days

Example D: If the patient in examples B and C is admitted for the surgical treatment on 07/04/2003 then the waiting time from urgent referral to treatment is calculated as follows.

Waiting time from urgent referral to first treatment
= START DATE (SURGERY HOSPITAL PROVIDER SPELL) - CANCER REFERRAL DECISION DATE – WAITING TIME ADJUSTMENT (FIRST SEEN) - WAITING TIME ADJUSTMENT (DECISION TO TREAT) – WAITING TIME ADJUSTMENT (TREATMENT)
= 07/04/2003 – 03/02/2003 – 8 – 7 – 0
= 48 days

The timeline for examples B, C and D is:

CANCER REFERRAL DECISION DATE	First appointment cancelled by patient	DATE FIRST SEEN	Follow –up appointment cancelled by patient	Follow-up appointment (Attended)	DECISION TO TREAT DATE	START DATE
03/02/03	11/02/03	18/02/03	25/02/03	04/03/03	11/03/03	07/04/03
◄——► ADJUSTMENT (FIRST SEEN)		◄——► ADJUSTMENT (DECISION TO TREAT)				

References

http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/Cancer/CancerArticle/fs/en?CONTENT_ID=4001800&chk=dpRNWQ

- HSC 2001/012 - Cancer Waiting Times: Achieving the NHS Cancer Plan Waiting Times Targets, Department of Health.
- HSC 2002/005 - Cancer Waiting times: Guidance on Making and Tracking Progress on Cancer Waiting Times
- Achieving the two week standard: Questions and Answers
- Cancer Waiting Targets – A guide

http://www.performance.doh.gov.uk/cancerwaits/

- Cancer Waiting Times Data

http://nww.connectingforhealth.nhs.uk/nhais/cancerwaiting/documentation

- The user manual for the Cancer Waiting Database (including CSV upload format for multiple records)
- System security document

http://www.connectingforhealth.nhs.uk/nhais/products_and_services/vaprodopenexe/

- User Access form for Cancer Waiting Times System

http://www.connectingforhealth.nhs.uk/dscn/

- DSCN 22/2002 – National Cancer Waiting Times Monitoring
- DSCN 31/2003 – Extension of Active Monitoring to all tumour sites
- DSCN 15/2004 – Cancer Waiting Times – First Definitive Treatment
- DSCN 27/2004 – Cancer Waiting Times - Cancer Status

http://www.cancerimprovement.nhs.uk/View.aspx?page=/default.html

- ***Applying High Impact Changes to Cancer***
- ***The "How to" Guide: Achieving Cancer Waiting Times***
- ***Sustaining Cancer Waiting Times***

Discussion Forum

The discussion forum is designed to give the opportunity for those interested in cancer waits information to discuss ideas or share good practice.

To check out the discussion forum please visit:
http://www.nhsia.nhs.uk/discuss/login.asp?target=forum.asp?FORUM_ID=3

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