Better Cancer Care, An Action Plan

New Cancer Waiting Times Targets Data & Definitions Manual

Version 3.1 – 01 July 2010

Document Purpose	Definitions Manual for NHS Boards for the new cancer waiting times targets
Title	New Cancer Waiting Time Targets Definitions Manual
Author	Information Services Division of NHS National Services Scotland
Issue date	01 July 2010
Issue Version	3.1
Target Audience	NHS staff involved in implementing the new cancer waiting times targets and Scottish Government Policy Leads
Circulation List	NHS Board Chief Executives, Scottish Government Health Directors, National Tumour Groups, Regional Cancer Advisory Groups, National Waiting Times Delivery Group Scottish Primary Care Cancer Group Scottish Cancer Task Force
Cross References	1. Better Cancer Care, An Action Plan 2. Scottish Referral Guidelines For Suspected Cancer NHS HDL (2007) 9 3. NHS Scotland Cancer waiting Times National Data Definitions, update version from 01 October 2007
Superseded Documents	Data & Definitions Manual Version 1 (considered expired from 30 November 2009) Data & Definitions Manual Version 2 (considered expired from 31 January 2010) Data & Definitions Manual Version 3 (considered expired from 30 June 2010)

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1 Introduction

Better Cancer Care – An Action Plan was launched on 27 October 2008. Central to this is development of a comprehensive programme of work to assure the quality of care delivered. Two key and complimentary strands of this work are assuring compliance with national clinical standards and guidelines through robust clinical governance and delivery of 2 new cancer targets:

Target 1
62-day target to treatment for all patients referred urgently with a suspicion of cancer and for screened positive patients.

Target 2
31-day target from decision to treat to first treatment for all patients diagnosed with cancer irrespective of their route of referral.

These new targets have to be implemented and achieved in and from Quarter 4 (October – December) 2011.

This document aims to cover all the necessary definitions for implementing the new cancer waiting times targets, however if you have any further questions please contact NSS.ISDCancerWaitsNew@nhs.net

When considering the definitions for the new cancer waiting times targets, the Data & Definitions subgroup of the National Waiting Times Delivery Group (NCWTDG) noted that ideally these should align exactly with 18 weeks referral to treatment (RTT) definitions. However, it was concluded that cancer has a different cohort of patients, with different decisions and needs, from the cohort of elective care patients in 18 weeks RTT, but where appropriate definitions are aligned.

The following criteria were used as the basis for developing the definitions:

Clear & Transparent	Ensuring that the new cancer waiting times targets are easy to understand, both for patients and the public, and for the NHS staff responsible for ensuring that patients are able to start their treatment within the target timescales
Measurable	Avoiding any unnecessary increase in NHS data collection requirements within the context of existing or planned information systems
Resilient	The definition and scope of the targets need to remain workable and robust in the changing clinical and technological environment of NHS Scotland
Patient Focussed	Ensuring that the new cancer waiting time targets drive sustained improvements in patient experience and that patient choices are reflected within the definitions
Affordable	The targets must be achievable within the resources allocated to NHS Scotland by the Scottish Government

2 Responsibility for Delivering the Cancer Waiting Times Targets

What is Primary Care responsible for?

General practitioners are responsible for referring patients with a suspicion of cancer in line with the Scottish Referrals Guidelines for Suspected Cancer NHS HDL (2007) 9. In line with established best practice, referrals should be submitted electronically via SCI Gateway. Boards should ensure that practices are supported to achieve this. Practices should have systems in place to ensure that urgent referrals with a suspicion of cancer are submitted on the same or the day following the decision to refer.

Exceptionally, where electronic methods are not available, referrals to secondary care providers should be sent as soon as possible. NHS Boards should audit levels and efficiency of electronic and other referral methods.

Which Board is responsible for delivering the 62-day target?

The Board of receipt of referral is responsible for meeting 95% compliance with the 62-day target.

Which Board is responsible for delivering the 31-day target?

The Board of first treatment is responsible for meeting 95% compliance with the 31-day target.

A 5% tolerance level will be applied to the cancer targets to allow for patients whom it is not appropriate or advisable to expedite through the system for the purpose of achieving target compliance.

If a NHS Board chooses to outsource part of a patient's care (e.g. to the independent sector or NHS England) the responsibility for delivering the target will remain with the relevant NHS Board.

3 Data Collection and Publication

Who is responsible for collating and submitting the data?

The Board responsible for collating and submitting the data is the Board of receipt of the initial referral to secondary care. Data for both performance management and official reporting of the new targets should come from a single source - the tracking systems within Boards. This will be subject to the same degree of scrutiny, validation and quality assurance as current methods of target performance measurement.

When and how should the data be reported?

The data should be submitted to the Information Services Division (ISD) of NHS National Services Scotland monthly via SWIFT (Submission With Internet File Transfer), based on patients treated within the month. This should be submitted once per Board for all tumour sites by the 20th of the following month. If the 20th falls on a weekend or public holiday, the data should be submitted the next working day. The submission timetable can be found on the New Cancer Waiting Times page (http://www.isdscotland.org/isd/5013.html).

A complete resubmission with any missing patient details can be made to ISD, up until the deadline. Data for the quarterly publication can be submitted one month after the submission deadline of the last month in that quarter, e.g. Quarter 1 (January – March) the submission deadline month will be May.

Any submission queries should be directed to NSS.ISDCancerWaitsNew@nhs.net

Data Validation

Validation of submitted data will be carried out by ISD on uploading of the data. This is a series of logic checks to see if the data is feasible, e.g. if the patient is born before they are referred for treatment. The SWIFT system will not accept the Board submission if any of these logic checks fail. It should be noted, however, that this is not a measure of accuracy of the data.

A second level of validation will occur at ISD, and specific anomalies will be brought to the attention of each Board. Examples of this are if the wait to treatment is over a year, or if the patient was referred a long time after they were treated.

Who is responsible for the accuracy and sign off of the publication data?

The Board responsible for signing off the accuracy of publication data is:
62-day target – The Board of receipt of referral
31-day target – The Board of first treatment

For some patients in the 31-day target cohort, it is possible that a Board other than the one that submits the data is responsible for delivering the target. Boards should have mechanisms in place for data submission and sign off for these patients.

NHS Boards are required to sign off publication data via an NHS Board nominee. The nominee will have overall responsibility for sign off and ensuring that sign off occurs if they are not available.

NHS Board contacts are broken down as follows:

- Sign off contact – NHS Board nominee responsible for sign off
- Main contact – NHS Board nominee identified as ISDs main point of contact for all communication
- Alternative contact – NHS Board nominee identified as an alternative contact for communication

ISD will distribute reports and sign off documentation to the main and alternative contact for each board (within 5 working days) of generating the quarterly extract. Sign off should be received (within 5 working days) from the sign off contact by emailing NSS.ISDCancerWaitsNew@nhs.net.

Publication Revisions

If after publication it transpires that the data originally submitted was incomplete or incorrect, NHS Boards will be given the opportunity to re-submit the historical data. ISD will then revise the published data at the next quarterly publication starting in September 2010 (revising data published in June 2010). This will be in line with the NSS Statistical Revisions Policy and will align cancer waiting times with other ISD statistical releases and should ensure openness, transparency and the most up-to-date and relevant data being used for publication.

The latest published data will be used for the generation of responses to information requests, parliamentary questions, etc.

Publication Timetable - published quarterly based on quarter of treatment

Target	**Start collecting data on patients treated from**	**First submission of data to ISD**	**First publication**	**Publication period covered**
New 62-day excluding screening	1st Sept 2009	20th Oct 2009	29th June 2010	Quarter 1 (Jan – Mar 2010)
New 31-day excluding screening*	1st Sept 2009	20th Oct 2009	28th Sept 2010	Quarter 2 (Apr – June 2010)
New 31- and 62-day including screening	1st March 2010	20th April 2010	21st Dec 2010	Quarter 3 (July – Sept 2010)
New 31- and 62-day including all cervical patients	1st May 2010	21st June 2010	22nd Feb 2011	Quarter 4 (Oct – Dec 2010)

The publication timetable above will depend on the quality of the new target data and its fitness for publication ISD will work in partnership with the UK Statistics Authority for the statistics of the new cancer waiting times targets to become National Statistics.

4 Performance and Quality Measures

Quality Standards for Cancer Services

There are many standards for Quality Assurance and accreditation of clinical cancer services in NHS Scotland, some of which measure performance of an aspect of waiting time for patients, e.g. NHS Quality Improvement Scotland standards.

For those services involved in measuring against the quality standards, the new cancer waiting times targets supersede the standards for the purposes of performance management of cancer access.

Adult acute leukaemia and paediatric cancers

The 31-day urgent referral to treatment standards for adult acute leukaemia and paediatric cancers will remain and data submission will continue.

HEAT

The new 31- and 62-day targets are both included as performance measures in HEAT 2010/11.

Quality Assurance

The Data Quality Assurance (DQA) Team of ISD assesses and advises on all aspects of data quality including accuracy, consistency, completeness and definitions. It is anticipated that a timetable of retrospective quality assurance for the new cancer targets will be established once submitted data is fit for publication.

It is important that the performance against the new cancer waiting times targets is measured in conjunction with the number of cancer patients in NHS Scotland to assess coverage of the application of the targets. ISD will continue to monitor case ascertainment figures compared with cancer registrations. For this reason data on all patients in the cancer waiting times targets cohort (see section 5) will be required for the analysis, including patients who will be excluded from performance calculation.

5 Cancer Waiting Times Targets Cohort

The cancer waiting times targets are applicable to adult (over 16 at date of diagnosis) NHSScotland patients with a newly diagnosed primary cancer. NHS Boards should ensure patients are over 16 at diagnosis prior to data submission. Recurring cancers are not covered by these waiting times targets. For further details of which cancer types should be included in waiting times submission see page 18.

The **62-day target** applies to patients who:

- were referred urgently by a primary care clinician or General Dental Practitioner (GDP) with a suspicion of cancer;
- were detected through the National breast, bowel and cervical Screening Programmes; or
- attended A&E or were referred directly to hospital.

The **31-day target** applies to all patients irrespective of route of referral.

Patients should be included in the relevant waiting times target cohort when they have part of or their entire pathway within NHSScotland. Patients who choose to have part of their pathway out with NHSScotland will be exempt from the relevant target as follows:

- If the part of their pathway outwith NHSScotland is pre decision to treat the patient will not be subject to the 62-day target, irrespective of route of referral. The patient will be subject to the 31-day target decision to treat to first treatment. For coding guidance please see page 16
- If the part of their pathway outwith NHSScotland is post decision to treat the patient will not be subject to the 62-day target or the 31-day target. As the patient is not subject to either of the cancer waiting times targets, data should not be submitted to ISD for these patients.

Applicable cancer types

Performance will be monitored on the following cancer types:

- Breast
- Colorectal
- Head & Neck
- Lung
- Lymphoma
- Ovarian
- Melanoma
- Upper Gastro-Intestinal (hepato-pancreato-biliary (HPB) and oesophago-gastric (OG))
- Urological (prostate, bladder, other)
- Cervical

Performance will **not** be monitored on the following cancer types:

- Carcinoma in situ (with the exception of breast, which is included)
- Some non-invasive tumours e.g. pTa tumours (see page 18)
- Mesothelioma
- All other tumour types not identified above

Wider coverage of monitoring of the targets to these and other cancer types will form part of future consultation with NHS Boards.

6 Dataset

For each patient the following data items need to be recorded:

	Field	Format	Mandatory?	Page
Patient Demographics	CHI Number	10 numbers	Yes	12
	Unique Care Pathway Number	TBC	No	12
	Hospital Patient Identifier	10 characters	No	12
	Patient Postcode at Referral	7 characters	Yes	13
	Ethnic Group	2 characters	Yes	13
Referral	Date of Receipt of Referral	DDMMYYYY	Yes, if a patient is in the 62-day target cohort	14
	Board of Receipt of Referral	1 character	Yes	15
	Urgency and Source of Referral	2 characters	Yes	16
Diagnosis	Cancer Type	2 characters	Yes	18
Decision To Treat	Date Decision to Treat	DDMMYYYY	Yes	19
First Treatment	Type of First Treatment	2 characters	Yes	21
	Date of First Treatment	DDMMYYYY	Yes	24
	Board of First Treatment	1 character	Yes	25
Waiting Times Adjustment	Waiting Time Adjustment Pre-DTT - Number of Days	Number	Yes	26
	Waiting Time Adjustment Pre-DTT - Main Reason	2 characters	Yes	26
	Waiting Time Adjustment Post-DTT - Number of Days	Number	Yes	26
	Waiting Time Adjustment Post-DTT - Main Reason	2 characters	Yes	26
Adjusted Length of Pathway	Referral to Treatment (days)	Number	Yes, if a patient is in the 62-day target cohort	32
	Decision to Treat to Treatment (days)	Number	Yes	32
Reason for Delay	Reason for Delay 62-day	2 characters	Yes	33
	Reason for Delay 31-day	2 characters	Yes	33

6.1 Person Demographics

6.1.1 CHI Number

Format: 10 characters

The Community Health Index (CHI) number is a unique numeric identifier, allocated to each patient on first registration with the system. The CHI number is a 10-character code consisting of the 6-digit date of birth (DDMMYY), two digits, a 9th digit that is always even for females and odd for males and an arithmetical check digit.

The CHI number should always be used to identify a patient. However, Health record identifiers, such as hospital numbers in Patient Administration Systems (PAS), may be used locally, in conjunction with the CHI number or in the absence of the CHI number, to track patients and their records.

Although there may be no number when a patient presents for treatment, there must be an allocation at some point in the episode of care as CHI is mandatory on all clinical communications.

6.1.2 Unique Care Pathway Number (UCPN)

Format: To Be Confirmed

This data item is under development with 18 weeks RTT and SCI teams.

6.1.3 Hospital Patient Identifier

Format: 6-10 alphanumeric characters

The hospital patient identifier is a code that uniquely identifies a patient on the main index of a hospital (i.e. within the hospital health records system). The code is normally allocated on the patient's first contact with the hospital except where the contact is through Accident & Emergency. This should be the identifier allocated at the hospital of initial referral.

6.1.4 Patient Postcode at Referral

Format:	**Example**
AN NAA	G5 8BW
ANN NAA	M34 3AB
AAN NAA	EH5 3SQ
AANN NAA	EH12 6UP
ANA NAA	W1A 4WW
AANA NAA	EC1A 1HQ
AAA NAA	GIR 0AA (only one in UK)

This is the postcode of the patient, as recorded on the referral. If not recorded, and for patients who are not resident in the UK, use the code NK01 0AA.

6.1.5 Ethnic Group

Format: 2 characters

This is self assigned by the patient, and should be sourced from the GP referral or the PAS system.

Code	Description
01	White
02	Mixed
03	Asian, Asian Scottish or Asian British
04	Black, Black Scottish or Black British
05	Other ethnic background
97	Not disclosed
99	Not known

A further list of subcategories can be found in the ISD Data Dictionary at http://www.datadictionaryadmin.scot.nhs.uk/isddd/11138.html

6.2 Referral

6.2.1 Date of Receipt of Referral

Format: DDMMYYYY

The date of receipt of referral is defined below for each referral source.

GP/GDP patients
The referral date is the date of receipt of initial referral into secondary care.

In line with established best clinical practice, referrals should be submitted electronically. For electronic referrals the date of receipt of referral is the GP submission date. In exceptional circumstances referrals can be made by letter, fax or telephone. For referral letters and faxes the date of referral is the date with which the referral is stamped as having first been received in secondary care. For telephone referrals this is the date the verbal communication took place.

N.B. This field is only mandatory for GP/GDP referrals that are urgent with suspicion of cancer. Other urgencies of referral can be coded 10/10/1010 (inapplicable).

Bowel Screening Programme patients
The referral date is the date a request for a further diagnostic intervention is sent via SCI gateway after a positive screening test is reported on the Bowel Screening System (BoSS).

Breast Screening Programme patients
The referral date is the date that the letter for the assessment centre is generated to request recall to an assessment centre for further diagnostic intervention.

Cervical Screening Programme patients
The referral date is the date when the smear is reported on the Scottish Cervical Call Recall System (SCCRS) and classed as a moderate or severe or above, grade of abnormality whereby a request is generated for a colposcopy.

A&E or other direct referral to hospital patients
The referral date is the date the patient presents to hospital (A&E or other).

Other referrals
For these referral types (coded 17 under Urgency and Source of Referral) this field is optional. Code 10/10/1010 (inapplicable) can be used.

Date not known
If no date is documented, use 09/09/0909 (not recorded). This would count as a breach of the 62-day target, if applicable.

Additional Information

Multiple referrals
It is possible for a patient to be referred in to secondary care and already be under a care pathway in secondary care. In this situation there should be a clinical decision as to whether this new referral overrides the current pathway or not, and therefore which target cohort the patient is in. This decision should be documented, and will determine the Date of Receipt of Referral.

Downgraded referrals
If an urgent referral with suspicion of cancer is downgraded in agreement with the GP (see page 17) the date of receipt of referral will no longer be a mandatory field.

Fast track referrals
Many NHS Boards have set up arrangements to enable GPs to refer directly for specific tests. Some NHS Boards also have set up arrangements whereby, if the results of this test highlight a suspicion of cancer, a referral is sent by 'fast track' directly to a hospital consultant and the GP is not required to send a referral for the patient . Where a NHS Board has an agreement between primary & secondary care that a GP referral is not required, the patient pathway should be managed within the 62-day target. In these cases the date of receipt of referral should be taken as the date of the report of the first open access investigation that triggered the 'fast track' process and this should be coded as GP urgent with suspicion of cancer.

For NHS Boards who do not have such an agreement in place between primary and secondary care and who require a GP referral, the urgency and date of receipt of referral should be recorded as dictated by the GP referral received.

6.2.2 Board of Receipt of Referral

Format: 1 character
This is the Board that receives the initial referral into secondary care. For breast screening referrals the Board of receipt of referral is the screening unit's host Board, e.g. women in NHS Lanarkshire are screened by a unit hosted by NHS Greater Glasgow & Clyde and therefore NHS Greater Glasgow & Clyde would be the Board of receipt of referral.

Code	Description
A	NHS Ayrshire & Arran
B	NHS Borders
Y	NHS Dumfries & Galloway
F	NHS Fife
V	NHS Forth Valley
N	NHS Grampian
G	NHS Greater Glasgow & Clyde
H	NHS Highland
L	NHS Lanarkshire
S	NHS Lothian
R	NHS Orkney
Z	NHS Shetland
T	NHS Tayside
W	NHS Western Isles

6.2.3 Urgency and Source of Referral

Format: 2 characters

This combines the urgency and source of the initial referral to secondary care.

To determine if a referral should be coded '14' as 'Urgent with a Suspicion of Cancer' apply the following:

For SCI referrals or template/proformas: the urgency should be taken from the urgency/priority field in the top section of the letter, and not determined from the free text/body of the letter

For other methods of referral: the letter/fax/phone call must clearly indicate if urgent with suspicion

Code	Description
02	Referral from a National Cancer Screening Programme
14	Primary care clinician or GDP urgent referral with suspicion of cancer
15	Direct referral to hospital (self, GP or NHS24 referral to A&E or other)
16	GP/GDP referral other
17	Other

Additional Information

62-day target cohort
Patients who are referred as 'Type of Referral' 02, 14 or 15 are in the cohort for the 62-day target.

Incidental findings
A referral should be considered an incidental finding and coded 17 (Other) if one of the following applies:

- the cancer diagnosed does not relate to the symptoms of the initial referral to secondary care
- the cancer diagnosed does not relate to the symptoms of direct referral to hospital (A&E or other)
- the cancer diagnosed is a cancer other than that for which the patient was screened.

Multiple referrals
It is possible for a patient to be referred in to secondary care and already be under a care pathway in secondary care. In this situation there should be a clinical decision as to whether this new referral overrides the current pathway or not, and therefore which target cohort the patient is in. This decision should be documented, and will determine the Urgency and Source of Referral.

Downgrading referrals
The urgency and source of referral may be downgraded from 14 (Primary care clinician or GDP urgent referral with suspicion of cancer) if the primary and secondary clinicians agree the referral did not meet the Scottish Referral Guidelines for Suspected Cancer. The result of this correspondence must be clearly documented. Downgraded referrals should be coded as the agreed urgency of referral, i.e. 16 (GP/GDP referral other) or 17 (Other).

Upgrading referrals
Referrals upgraded by a consultant to urgent with suspicion of cancer should be coded as 16 (GP/GDP referral other) or 17 (Other) as received, but this should not affect their clinical care. If a patient is diagnosed with cancer they will then be subject to the 31-day target from decision to treat to treatment.

Pathways outwith NHSScotland – Patient Choice
If a patient chooses to have part of their diagnostic pathway outwith NHSScotland, but has the decision to treat to treatment within NHSScotland, this should be coded 17 (Other).

6.3 Diagnosis

6.3.1 Cancer Type

Format: 2 characters

The cancer type must fit into one of the thirteen cancer types below to be included in the target.

Code	Description	ICD-10 Codes included	Exclusions, if applicable
01	Breast	C50, D05 All patients with a new primary breast cancer or carcinoma-in-situ	None
02	Colorectal	C18-20	Sarcoma, lymphoma or carcinoid tumours
03	Head & Neck	C00-14, C30-32, C76.0,	
04	Lung	C33-34	Mesothelioma, cancer of pleura
05	Lymphoma	C81-85	
06	Melanoma	New primary invasive (i.e. Clark level > 1) melanoma of any site except eye. Includes C43 (Skin) Proven secondary melanoma where the origin of the primary lesion has never been identified.	In situ disease i.e. Clark level ≤ 1 Melanoma of eye (choroidal, conjunctival) Patients with recurrent disease rather than a new primary
07	Gynaecological – Ovarian	C56, C48 (only if ovarian type), D39.1	
08	Upper GI – Hepatopancreatobiliary	C22-25	
09	Upper GI – Oesophagogastric	C15-16, C17.0	Lymphoma, carcinoma-in-situ, high grade dysplasia
10	Urology – Bladder	C67	Non-invasive tumours
11	Urology – Prostate	C61	Patients with non-invasive tumours (e.g. prostatic intraepithelial neoplasia)
12	Urology – Other	C60, C62-66, C68	
13	Gynaecological – Cervical	C53	D06, CIN 1, CIN 2 and CIN3

Some patients never have microscopic verification of the tumour (i.e. histology or cytology). In these cases diagnosis is made on information such as imaging investigations. For waiting times purposes, if a patient has been told they have cancer and/or have received treatment for cancer, then the relevant primary diagnosis code should be used. Include patients even though they have had a previous primary malignancy of any cancer site or a concurrent primary malignancy of another cancer site. But if the origin of the primary tumour cannot be determined, it should not be included in waiting times. Recurrent cancer is not included in the target. Metastatic cancers (except melanoma where the origin of the primary lesion has never been identified) are also not included in the target. With the exception of breast, carcinoma in situ tumours are not included.

6.4 Decision to Treat Date

Format: DDMMYYYY

Following MDT discussion, the date on which the treatment plan was agreed between the patient and the clinician (or delegate) responsible for first treatment. Where there are two possible dates, the earliest date applies.

Notwithstanding target delivery, it is in the best interests of patient care that in all cases the decision to treat discussion with the patient should take place as soon as possible after the MDT meeting. NHS Boards should audit the interval between these dates and take appropriate action to ensure that delays are avoided.

Additional Information

If the first treatment is to be surgery:
This is the date that the consultation between the patient and the surgeon (or delegate) responsible for first treatment took place and a treatment plan for surgical treatment was agreed.

If the first treatment is to be chemotherapy or other drug treatment:
This is the date that the consultation between the patient and the oncologist (or delegate) responsible for first treatment took place and a treatment plan for chemotherapy treatment was agreed.

If the first treatment is radiotherapy:
This is the date that the consultation between the patient and the oncologist (or delegate) responsible for first treatment took place and a treatment plan for radiotherapy treatment was agreed.

If a decision is taken to provide supportive care:
This is the date that the consultation between the patient and clinician took place and a plan for supportive care was agreed

If the first treatment is active monitoring:
This is the date that the consultation between the patient and the clinician responsible for active monitoring took place and a plan for active monitoring was agreed.

Patient dies or refuses treatment
If a patient dies before treatment or refuses all treatment the date of decision to treat should be recorded as either the date decision to treat occurred or 10/10/1010 (inapplicable).

Date not known
If no date is documented, use 09/09/0909 (not recorded). This would count as a breach of the 31-day target.

Example decision to treat scenarios

Scenario 1
Patient is diagnosed with breast cancer and discussed at MDT. The treatment plan is decided as surgery with a surgeon in that NHS Board. The surgeon telephones the patient the next day to discuss the MDT decision and the patient agrees to surgery. The date of decision to treat is the date of the telephone conversation.

Scenario 2
Patient is diagnosed with oesophageal cancer and discussed at MDT. Surgery is decided as treatment but the patient is frail and requires a high risk anaesthetic assessment. The surgeon and patient agree on surgery as treatment pending the anaesthetic assessment and they agree that a further appointment will not be necessary unless the opinion of the anaesthetist is that surgery is too risky. The anaesthetist sees the patient and assesses him fit for surgery and the patient is listed for surgery. The date of decision to treat is the date of the anaesthetic assessment.

Scenario 3
Patient is diagnosed with lung cancer. MDT discussion concludes that surgery at a tertiary NHS Board is the best plan for this patient. The patient comes in to see their local lung physician who discusses the option of thoracic surgery at a different NHS Board. A referral is made to the tertiary service and the patient meets the thoracic surgeon two days later. They discuss the operation in more detail, including some information not mentioned at the previous consultation. The patient agrees to go ahead with the surgery. The date of decision to treat is the date of the discussion between the patient and thoracic surgeon.

Scenario 4
Patient is diagnosed with colorectal cancer. The MDT discussion concludes that this patient should have neo-adjuvant chemoradiotherapy at a tertiary NHS Board followed by surgery in their local NHS Board. The colorectal clinical nurse specialist knows the patient well and offers to discuss the treatment options with the patient. The patient is referred to and attends an oncology appointment at the tertiary NHS Board, and agrees to go ahead with the chemoradiotherapy. After the course of chemoradiotherapy the patient has an appointment in their local NHS Board and subsequently attends for surgery. The date of decision to treat is the date of the outpatient consultation with the oncologist at which the patient decides to opt for chemoradiotherapy

Scenario 5
A patient has a skin lesion which the dermatologist removes completely in the course of a biopsy. The pathology suggests that although it is a melanoma, no further treatment is indicated. In this case the date of first treatment should be used as the decision to treat.

6.5 First Treatment

6.5.1 Type of First Treatment

Format: 2 characters

The definition of first treatment is the treatment or drug that genuinely attempts to begin the patient's first treatment, including if this is palliative care or supportive care. Cancer waiting times definitions have been formed for performance monitoring and not for clinical outcome purposes. Patients should be included in the target where a first treatment was attempted, but either not carried out or not completed for clinical reasons, e.g. 'open and shut' cases would be included under 01 'Surgery'. Diagnostic biopsies should only be included if the whole tumour has been removed and margins are clear.

Code	Description
01	Surgery
02	Radiotherapy
03	Chemotherapy
04	Synchronous chemoradiotherapy
05	Endoscopic
06	Hormone therapy
07	Supportive care
08	Patient refused all treatment *
09	Not recorded ~
11	Other
12	Watchful wait/active surveillance
14	Patient died before treatment *

* Patients who die before treatment or who refuse all treatment will be excluded from the cancer waiting times targets.
~ Patients coded as 09 will be calculated as a breach of any eligible target.

The following pages contain guidelines of recognised first treatment types, based on queries received by the cancer surveillance team of the Epidemiology and Statistics Group of ISD.

Recognised First treatments – General

The summary table below is based on queries received by the cancer surveillance team of the Epidemiology and Statistics Group of ISD. The cancer surveillance team advise that this list is not exhaustive and continue to advise on queries from Boards on definition of first treatment. Further queries should be sent to NSS.ISDCancerWaitsNew@nhs.net

Please see tables in Appendix 1 for additional tumour specific first treatment types.

01	Surgery	Examples include: ▪ partial or total resection of the primary tumour and/or metastases ▪ palliative procedures, e.g. to bypass obstructive lesions ▪ debulking ▪ transplants ▪ procedures converted from laparoscopic to open surgery ▪ intra-operative radiotherapy ▪ 'open & shut' cases ▪ wide local excision (WLE) ▪ therapeutic laparoscopic surgery Does not include diagnostic biopsies such as punch, incisional, needle or core etc. unless all tumour removed and margins were clear.
02	Radiotherapy	Examples include: ▪ neoadjuvant ▪ radical ▪ palliative ▪ brachytherapy Additionally this includes radiotherapy to metastatic site prior to treatment of primary site.
03	Chemotherapy	Examples includes: ▪ neoadjuvant ▪ primary ▪ palliative ▪ new drugs given as part of a clinical trial, even if a placebo
04	Synchronous Chemoradiotherapy	Where chemotherapy and radiotherapy treatments are combined and administered concurrently/synchronously.
05	Endoscopic	Examples include: ▪ endoscopic laser therapy ▪ argon beam therapy ▪ endomucosal resection ▪ photodynamic therapy (PDT) ▪ stenting ▪ cystodiathermy ▪ panendoscopic debulking Use code 07 if dilatation is carried out as a supportive care procedure.

06	Hormone therapy	Includes new drugs given as part of a clinical trial, even if a placebo.
07	Supportive care	Requires that a clinical decision has been made and agreed with the patient for supportive care only (which might mean no intervention). Examples of symptom control intervention include: ▪ blood transfusion ▪ percutaneous endoscopic gastrostomy (PEG) ▪ draining of pleural or ascitic fluid and insertion of kaolin if these were the only treatment given ▪ steroids given for initial stabilisation or palliative care ▪ analgesics ▪ antiemetics ▪ dilatation ▪ complementary alternative therapies ▪ psychological support ▪ Specialist Palliative Care consultation ▪ nursing care ▪ tracheostomy, if no other treatment carried out ▪ antibiotics, if no other treatment carried out The patient may receive subsequent treatment after a variable interval. Does not include treatments given for other conditions e.g. warfarin for stroke patients subsequently diagnosed with cancer.
11	Other therapy	Examples include: ▪ stent insertion (other than endoscopic) ▪ bisphosphonates ▪ biological therapy (including immunotherapy and biological response modifiers) ▪ liver embolisation ▪ alcohol injections ▪ helicobacter eradication therapy ▪ radio ablation therapy
12	Watchful wait / active surveillance	Requires that a clinical decision has been made and agreed with the patient for no active treatment at this time, but the patient may receive subsequent treatment after a variable interval.

6.5.2 Date of First Treatment

Format: DDMMYYYY

This is the date of first cancer treatment. The table below gives guidelines for date of treatment per treatment type.

Mode of first treatment	Date of first treatment
Surgery	Date of surgery (not date of admission)
Radiotherapy	Date of first fraction
Chemotherapy	Date of first pulse
Synchronous chemoradiotherapy	Date of first pulse
Endoscopic	Date of procedure
Hormone therapy	Date of communication to GP requesting prescription plus 2 days, or date of prescription if given directly to patient.
Supportive care	Date symptom control intervention commences. If no symptom control intervention planned the date of decision to treat should be used.
Patient refused all treatment	Date patient refused any treatment
Not recorded	09/09/0909 (not recorded) N.B. This will be counted as a breach of any eligible target.
Other	Date of other documented first treatment
Watchful wait/active surveillance	Date of decision to treat
Patient died before treatment	Date of death, as on death certificate

6.5.3 Board of First Treatment

Format: 1 character

This is the Board who has responsibility for the first (intended) treatment.

Code	Description
A	NHS Ayrshire & Arran
B	NHS Borders
Y	NHS Dumfries & Galloway
F	NHS Fife
V	NHS Forth Valley
N	NHS Grampian
G	NHS Greater Glasgow & Clyde
H	NHS Highland
L	NHS Lanarkshire
S	NHS Lothian
R	NHS Orkney
Z	NHS Shetland
T	NHS Tayside
W	NHS Western Isles
D	Golden Jubilee National Hospital

If first treatment is performed out with an NHS Scotland Board, the Board that outsourced the treatment should be coded here.

6.6 Waiting Times Adjustment

On reflection of a whole patient pathway there may be some areas of delay not attributable to Board performance. These pathways may be adjusted to discount periods of patient unavailability, for patient-induced delays and medical suspensions. It is recognised that these adjustments can be complex to record and quality assure, however consultation showed that it is the right thing to do for measuring performance on waiting times for cancer patients, and aligns to wider waiting times principles and measurement across NHS Scotland.

Consultation also concluded that there cannot be a maximum length of adjustment or maximum number of adjustments allowed. As such, a record should be taken of all adjustments in the pathway, and on completion of the pathway all adjustments added together for submission. It will be important to check whether the adjustment occurs before or after the decision to treat, as adjustments can be made to both the 62- and 31-day targets. Each adjustment should be documented – if there is no documented evidence an adjustment cannot be made.

6.6.1 Waiting Times Adjustment Pre/Post-DTT – Number of Days

Format: Number

This is the cumulative number of days by which the waiting times pathway can be adjusted before/after the decision to treat. This can equal 0.

For each adjustment, the number of days should be calculated on the basis of the patient unavailability being an inclusive period. The dates should be the start date of unavailability and the end date of unavailability. Availability for the patient begins on the next subsequent date e.g.

The patient becomes unavailable on 3rd of May until the 1st of June. The patient is then available to continue their pathway on 2nd June. This would total as a 30 day adjustment. 2nd June minus 3rd May = 30 day adjustment.

6.6.2 Waiting Times Adjustment Pre/Post-DTT – Main Reason

Format: 2 characters

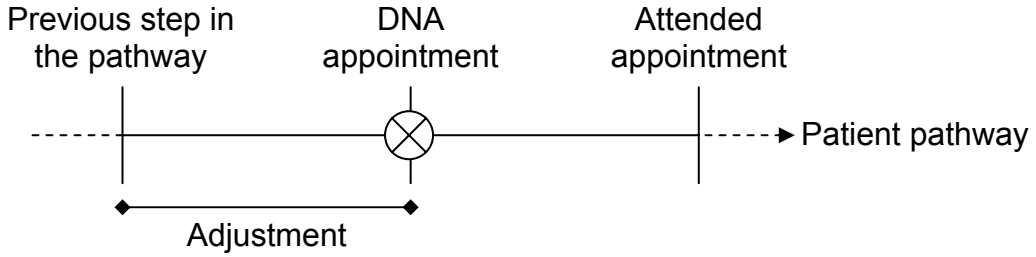
The main reason for the number of days adjustment before/after the decision to treat is the one that contributed the longest delay, or if two are equal, the first delay that occurred.

Code	Description
01	Patient did not attend
02	Patient cancelled
03	Patient defers
04	Temporary co-morbidity
05	Other patient-induced suspension
06	Medical suspension
07	No adjustment

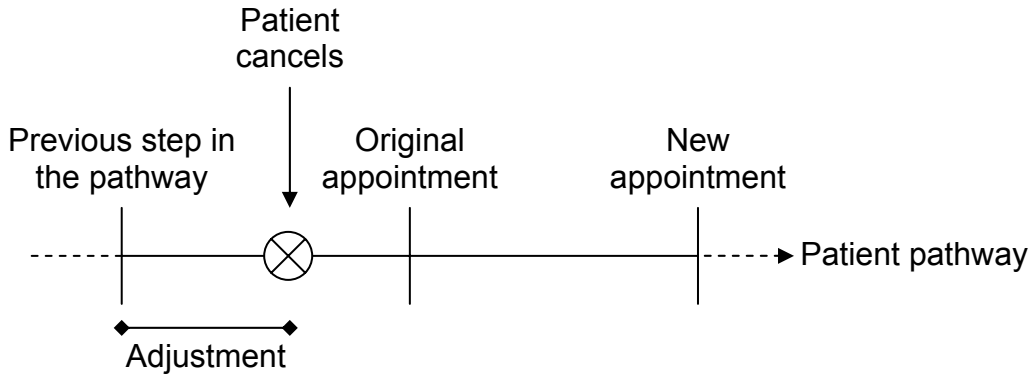
Adjusted Waiting Times Scenarios

In this section "appointment" should be taken to mean any pathway step, e.g. referral, clinic, test, treatment. "Waiting list" should be taken to mean the wait to any pathway step.

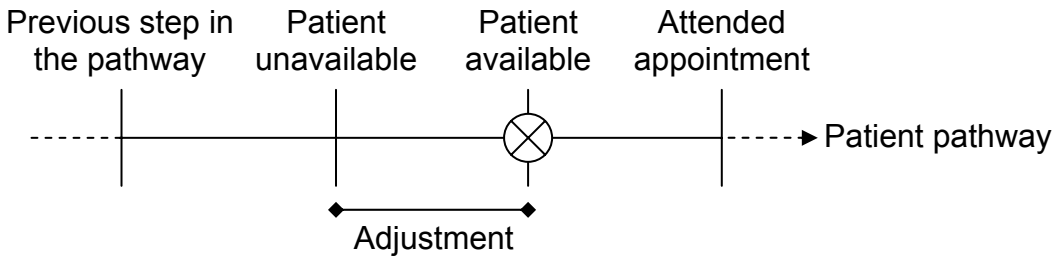
01 - Patient did not attend
If a patient does not attend an appointment a waiting times adjustment can be applied. **Adjustment is from DNA'd appointment back to previous step in the pathway.**



02 - Patient cancelled
A patient may have to cancel a booked appointment. **Adjustment is from date the patient cancelled their appointment back to previous step in the pathway.**

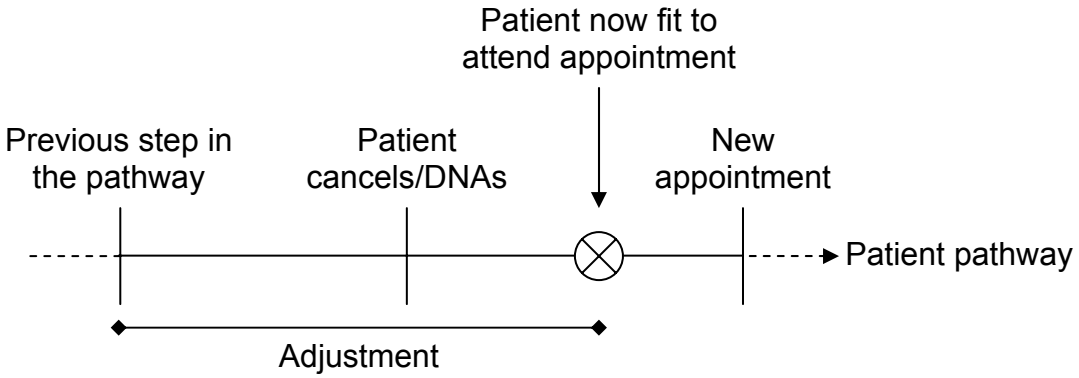


03 - Patient defers
Patients may choose to defer the next appointment until after a holiday or until they can make arrangements for other commitments. **Adjustment is the length of unavailability, e.g. length of time patient is on holiday.**



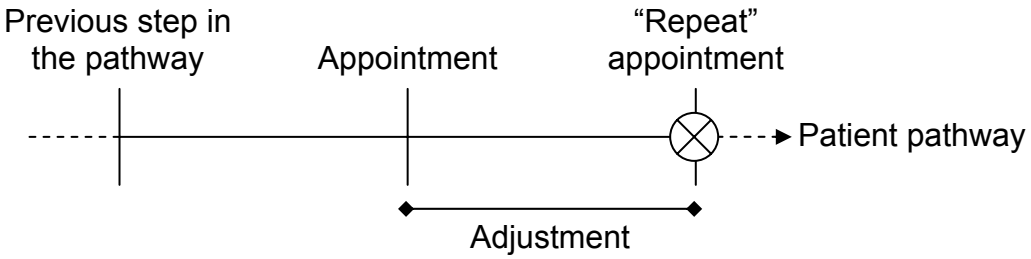
04 - Temporary co-morbidity

The patient has or develops an illness or condition that makes the patient unfit to attend for a diagnostic investigation or treatment, e.g. viral infection, neutropaenia, exacerbation of a chronic or pre-existing condition like chest disease or hypertension. **Adjustment is from the date the patient is fit to attend the next appointment back to the previous step in the pathway.**



05 - Other patient-induced suspension

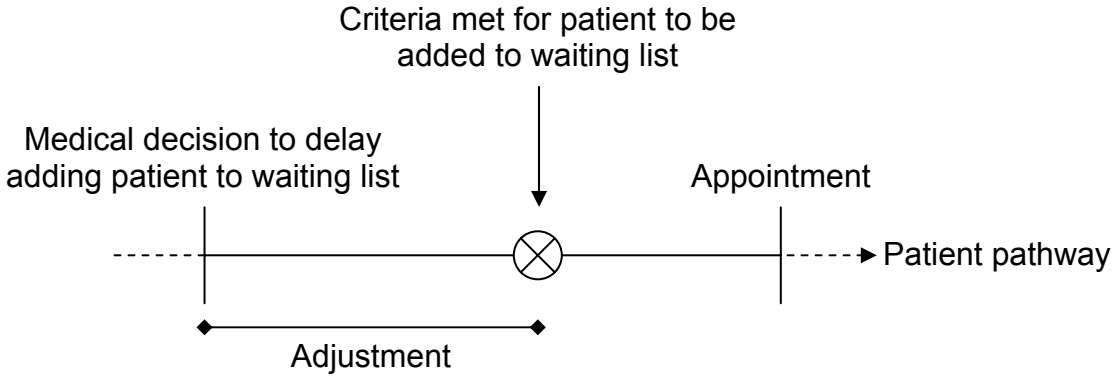
Occasionally a patient may require a repeat appointment in their pathway, because they choose to take some time to think over their options, or because they did not follow pre-appointment instructions such as bowel prep or stopping a medication. **Adjustment is from the repeat appointment back to the first.**



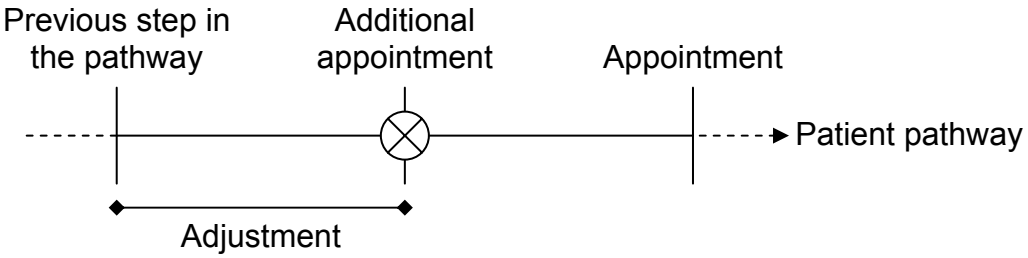
06 - Medical suspension

Medical suspension should be used when an additional and necessary pre-treatment step is required, or when a step in the pathway has to be delayed because an unacceptable risk would be incurred if that step were to take place within a fixed time period. Below are a few examples of medical suspension.

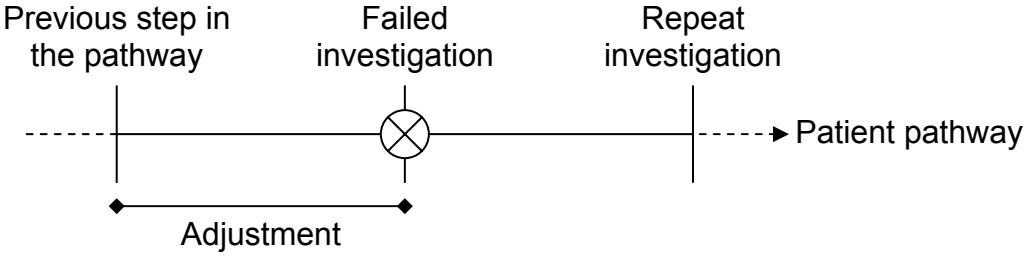
1. Patient deemed not fit for the next step in the pathway until certain criteria met, i.e. patient not to be added to waiting list until their general condition allows (e.g. optimal nutritional status met, patient recovered from previous procedure, for pregnant women waiting until foetus is viable). **Adjustment is from date ready for next step back to previous step, i.e. date medically fit to be placed on waiting list for appointment back to date unfit to continue.**



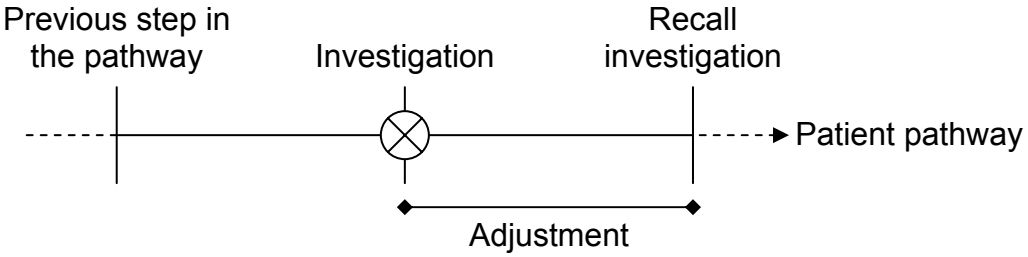
2. Patient needs a pre-treatment step that is not part of a routine pathway for that cancer, e.g. dental clearance, extra investigation to participate in a clinical trial, second opinion. **Adjustment for this is the extra time taken away from the routine pathway.**



3. Investigation failed and needs to be repeated as soon as possible. **Adjustment is from failed investigation back to previous step in the pathway.**

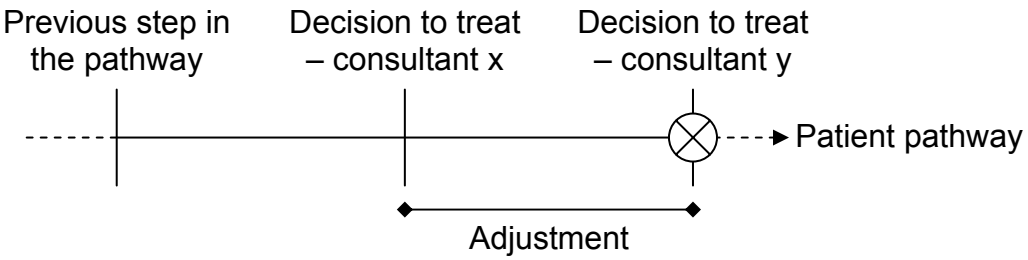


4. At diagnostic test no cancer is diagnosed, however cancer still suspected. Continue to track the patient and recall for a repeat diagnostic in a few weeks. **Adjustment is from the diagnostic test until the recall diagnostic.**

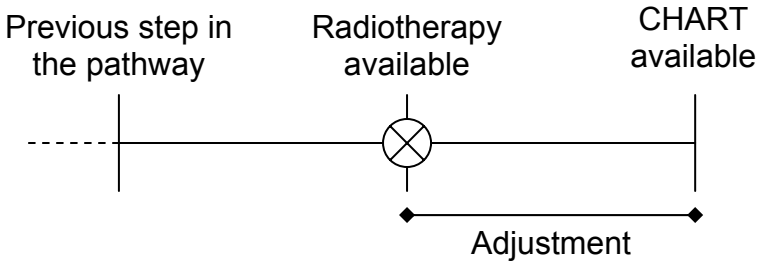


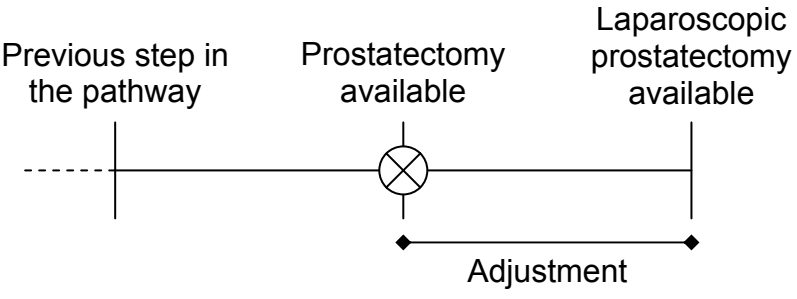
N.B. If after a diagnostic test cancer was no longer suspected the patient would be removed from tracking onto a review pathway. If a future diagnostic test produced a positive cancer diagnosis this patient would be included in the 31-day target only.

5. If an agreed treatment type is no longer appropriate, or if a patient changes their decision to a different specialty, an adjustment may be made between the two different decision to treats. **Adjustment is from the second decision to treat with clinician y back to the previous decision to treat with clinician x.**



6. Two treatments have been identified as not being available in all regional networks – CHART (continuous hyperfractionated accelerated radiotherapy for lung cancer) and laparoscopic prostatectomy. This is considered inequitable and penalises those NHS Boards that provide additional services and have the burden of responsibility for providing first treatment for meeting the 31-day target. Treating and referring NHS Boards in regions where such a treatment is offered can apply waiting times adjustments. **Adjustment is from the date that the treatment is available back to when an alternative treatment would have been available to the patient.**





7. For valid reasons, new and emerging technologies cannot be simultaneously and equitably established across NHSScotland. Guidance is currently being prepared for how waiting times adjustments should reflect this. Any new or emerging technology that is causing a potential delay to a patient pathway should be flagged through the Query Log. **Adjustments are not currently applicable to delays caused by new and emerging technologies.**

07 - No adjustment

Problems resulting from hospital operational circumstances should not result in any detriment to the patient; for example, the cancellation of a clinic at short notice, or appointments being cancelled or moved by the hospital. Therefore, waiting times adjustments cannot be made in these situations.

6.7 Adjusted Length of Pathways

6.7.1 Referral to Treatment

Format: Number

This is the number of days from referral to treatment, after any adjustment. This is:

Referral to Treatment = *Total number of days from referral to treatment*
minus
Total waiting times adjustment

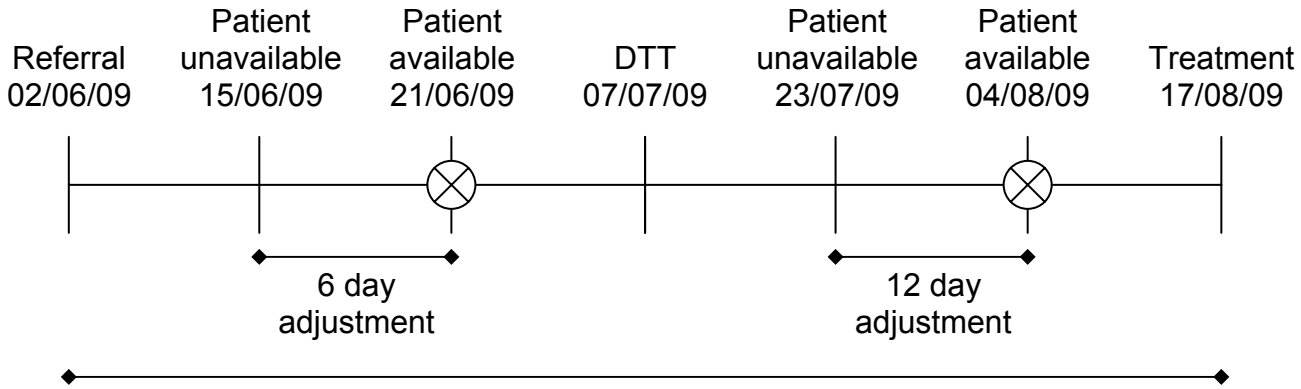
6.7.2 Decision to Treat to Treatment

Format: Number

This is the number of days from decision to treat to treatment, after any adjustment. This is:

Decision to Treat to Treatment = *Total number of days from decision to treat to treatment*
minus
Waiting times adjustment post DTT

Example
2nd June, patient is referred urgently with suspicion of cancer. Patient goes on holiday from 15th June to 20th June (inclusive). They have a decision to treat on 7th July. Patient is medically unavailable between 23rd July and 3rd August (inclusive). Patient receives first treatment on 17th August. This diagram shows the adjusted lengths of pathways:



Referral to treatment = 76 days
Total waiting times adjustment = 18 days
Adjusted length of pathway - Referral to Treatment = 58 days

Decision to Treat to Treatment = 41 days
Waiting times adjustment post-DTT = 12 days
Adjusted length of pathway - decision to treat to treatment = 29 days

6.8 Reason for Delay 62-day/31-day

Format: 2 characters

This field should be used to indicate the main reason for a breach of target, after the waiting time has been adjusted. The main reason is the one that contributed the longest delay, or if two are equal, the first delay that occurred.

Code	Description
11	Staffing issues (e.g. through vacancies, annual leave or illness)
12	Lack of other resources (e.g. theatre, equipment, facilities)
13	Routine staging or further investigation
14	Clinically complex *
15	Administrative error
16	Initially not suspicious of cancer
17	Downgraded by consultant
18	Initially referred to another speciality
19	Range of treatment options offered but patient's choice not available within target
08	Other reason
09	Not recorded
10	Inapplicable

* Clinically complex patients will be excluded from the cancer waiting times targets.

Clinically Complex Patients

For those patients in whom there is ambiguity around the application of clinical complexity, open discussion is expected within teams though the final decision should rest with the NHS Board lead cancer clinician. The new definitions in this manual and the option for clock adjustments have been written to minimise the need to use this code but it is acknowledged that there will be situations where complexity applies. The following example scenarios have been provided guidance.

Scenario 1

A patient requires a particularly complex combination of scans and biopsies that are not part of a routine pathway for that cancer.

Scenario 2

There is genuine clinical uncertainty about the diagnosis and a final decision on whether the patient has cancer cannot be reached. 'Watchful wait' treatment applies only when a definite diagnosis is made, whereas clinical exclusion applies if the diagnosis is not reached despite exhaustive tests and some monitoring of the patient is still required.

Scenario 3

Complex staging and multiple investigations are required to determine an optimal treatment plan for an individual patient (and where waiting times adjustment is not practical). Boards should consult timed pathways agreed by Regional Managed Clinical Networks as a reference point.

Scenario 4

If the patient has an ongoing co-morbid condition for which any of the usual treatments are not recommended or appropriate and an alternative treatment is necessary.

Appendix 1 - Recognised Tumour Site Specific First Treatments

Breast

	Mode of Treatment	Recognised for breast cancer?	Additions to procedures listed in general table (page 22)
01	Surgery	Y	Includes: ▪ duct excision Does not include: ▪ sentinel node biopsies ▪ vacuum biopsies unless whole tumour removed and margins were clear
02	Radiotherapy	Y	
03	Chemotherapy	Y	
04	Synchronous Chemoradiotherapy	N	
05	Endoscopic	N	
06	Hormone therapy	Y	Includes: ▪ endocrine therapy, e.g. tamoxifen, letrozole including prescribed by a GP
07	Supportive care	Y	
11	Other therapy	Y	Includes: ▪ bisphosphonates for bone metastases ▪ imiquimod cream (immunotherapy) for Pagets disease
12	Watchful wait / active surveillance	Y	

Cervical

	Mode of Treatment	Recognised for cervical cancer?	Additions to procedures listed in general table (page 22)
01	Surgery	Y	Includes: ▪ excisional biopsy where margins are clear and/or patient wishes to retain fertility (LLETZ, SWETZ, NETZX, Cone biopsy) ▪ open or laparoscopic lymph node dissection Does not include: ▪ punch or other diagnostic biopsies unless whole tumour removed and margins were clear
02	Radiotherapy	Y	Includes: ▪ external beam
03	Chemotherapy	Y	
04	Synchronous Chemoradiotherapy	Y	Includes: ▪ primary chemoradiation
05	Endoscopic	N	
06	Hormone therapy	N	
07	No active treatment (Supportive care)	Y	Includes: ▪ palliative radiotherapy for control of bleeding
11	Other therapy	Y	Includes: ▪ laser therapy
12	Watchful wait / active surveillance	Y	

Colorectal

	Mode of Treatment	Recognised for colorectal cancer?	Additions to procedures listed in general table (page 22)
01	Surgery	Y	Includes: ▪ laparotomy ▪ colostomy ▪ ileostomy ▪ defunctioning stoma/loop colostomy/ ileostomy
02	Radiotherapy	Y	
03	Chemotherapy	Y	
04	Synchronous Chemoradiotherapy	Y	
05	Endoscopic	Y	Includes: ▪ polypectomy at colonoscopy
06	Hormone therapy	N	
07	Supportive care	Y	
11	Other therapy	Y	
12	Watchful wait / active surveillance	Y	

Head & Neck

	Mode of Treatment	Recognised for head & neck cancer?	Additions to procedures listed in general table (page 22)
01	Surgery	Y	Includes: ▪ neck dissection ▪ curettage if tumour removed for therapeutic benefit
02	Radiotherapy	Y	
03	Chemotherapy	Y	
04	Synchronous Chemoradiotherapy	Y	
05	Endoscopic	Y	Includes: ▪ microlaryngoscopy to strip the vocal cord
06	Hormone therapy	N	
07	Supportive care	Y	
11	Other therapy	N	
12	Watchful wait / active surveillance	Y	

Lung

	Mode of Treatment	Recognised for lung cancer?	Additions to procedures listed in general table (page 22)
01	Surgery	Y	
02	Radiotherapy	Y	Includes: ▪ CHART
03	Chemotherapy	Y	
04	Synchronous Chemoradiotherapy	Y	
05	Endoscopic	Y	Does not include: ▪ mediastinoscopy without removal of whole tumour ▪ diagnostic bronchoscopy unless whole tumour removed and margins were clear
06	Hormone therapy	N	
07	Supportive care	Y	Includes: ▪ Pleurodesis and aspirate ▪ Drainage of pleural fluid to relieve breathlessness etc (i.e. if for therapeutic purposes) but not if for a sample for cytology
11	Other therapy	Y	
12	Watchful wait / active surveillance	Y	

Lymphoma

	Mode of Treatment	Recognised for lymphoma?	Additions to procedures listed in general table (page 22)
01	Surgery	Y	Includes: ▪ surgery if there is a therapeutic benefit
02	Radiotherapy	Y	
03	Chemotherapy	Y	
04	Synchronous Chemoradiotherapy	N	
05	Endoscopic	N	
06	Hormone therapy	N	
07	Supportive care	Y	
11	Other therapy	Y	Includes: ▪ steroids
12	Watchful wait / active surveillance	Y	

Melanoma

	Mode of Treatment	Recognised for melanoma?	Additions to procedures listed in general table (page 22)
01	Surgery	Y	Includes: ▪ diagnostic biopsy if whole tumour was removed and margins clear ▪ excision biopsy if it was intended to remove the whole tumour at first treatment.
02	Radiotherapy	Y	
03	Chemotherapy	Y	
04	Synchronous Chemoradiotherapy	N	
05	Endoscopic	N	
06	Hormone therapy	N	
07	Supportive care	Y	
11	Other therapy	N	
12	Watchful wait / active surveillance	Y	

Ovarian

	Mode of Treatment	Recognised for ovarian cancer?	Additions to procedures listed in general table (page 22)
01	Surgery	Y	
02	Radiotherapy	Y	
03	Chemotherapy	Y	
04	Synchronous Chemoradiotherapy	N	
05	Endoscopic	Y	
06	Hormone therapy	N	
07	Supportive care	Y	Includes: ▪ Pleurodesis
11	Other therapy	Y	
12	Watchful wait / active surveillance	Y	

Upper GI

	Mode of Treatment	Recognised for upper GI cancers?	Additions to procedures listed in general table (page 22)
01	Surgery	Y	Includes: ▪ liver transplant ▪ gastroenterostomy
02	Radiotherapy	Y	
03	Chemotherapy	Y	
04	Synchronous Chemoradiotherapy	Y	
05	Endoscopic	Y	Includes: ▪ Argon Plasma Coagulation (APC)
06	Hormone therapy	N	
07	Supportive care	Y	
11	Other therapy	Y	Includes: ▪ stent insertion by percutaneous transhepatic cholangiography (PTC) via guide wire ▪ portal vein embolisation
12	Watchful wait / active surveillance	Y	

Urology

	Mode of Treatment	Recognised for urological cancers?	Additions to procedures listed in general table (page 22)
01	Surgery	Y	Includes: ▪ bilateral orchidectomy for prostate cancer
02	Radiotherapy	Y	
03	Chemotherapy	Y	
04	Synchronous Chemoradiotherapy	N	
05	Endoscopic	Y	Includes: ▪ diathermy ▪ TURP carried out for therapeutic benefit for a suspected prostate cancer. If prostatic cancer is found incidentally at TURP (for what was thought to be benign prostatic hyperplasia) the TURP should not be considered first treatment. In this case first treatment is the treatment agreed with the patient postoperatively, e.g. watchful wait
06	Hormone therapy	Y	
07	Supportive care	Y	Includes: ▪ nephrostomy to alleviate symptoms or stabilise the patient
11	Other therapy	Y	Includes: ▪ Embolisation
12	Watchful wait / active surveillance*	Y	

* When patients with advanced or metastatic prostate cancer (not suitable for radical therapy) are not started on immediate androgen deprivation therapy, then the treatment is reserved until the time when the patient develops symptomatic progression. This is the traditional "watch and wait" situation. Patients with localised prostate cancer, who might be suitable for radical therapy, may be told that they have a choice between immediate radical therapy and "active surveillance". Here the follow-up is fairly intense, usually according to an agreed protocol and involves (usually) repeat clinic visits, repeat PSA and DRE, and often repeat biopsies after an interval. Progression in the disease, in the form of rising PSA, or change in grade of the tumour prompts a further offer of radical therapy.

Appendix 2 - Updates from previous versions

Version	Issue Date	Page Number (V3.1)	Summary of Changes
3.1	01 June 2010	5	Amended Responsibility For Delivering The Cancer Waiting Times Targets section
		6-7	Updated Data Collection and Publication section and deleted Current Target Based on Patients Diagnosed section.
		9-10	Updated Cancer Waiting Times Target Cohort section
		12	Inserted Format
		14	Update Bowel Screening Programme patients definition.
		15	Inserted additional information to Date of Receipt of Referral section.
		16-17	Inserted additional information to Urgency and Source of Referral section.
		18	Update paragraph in Cancer type section
		19	Insert information on patient dies or refuses treatment and date not known to Decision to Treat Date section.
		21	Update Type of first treatment definition.
		30-31	Insert additional waiting time adjustment scenarios.
		33	Update table in Reason for Delay 62-day/31-day section.
		37	Update head and neck additional information for Endoscopic procedure.
		38	Update lung additional information for Endoscopic procedure.

Acknowledgements

Kirsty Anderson, Principal Information Analyst, ISD
Jennifer Armstrong, Senior Medical Officer, Scottish Government
Gordon Birnie, Medical Director, NHS Fife
Karen Bonnar, Cancer Support Services Coordinator, NHS Forth Valley
Leigh Brown, Information Manager, ISD
Kathryn Burt, Information Analyst, ISD
Sarah Callaghan, Data Development Manager, ISD
Richard Carey, Chief Executive, NHS Grampian
Gillian Christie, Cancer Services Manager, NHS Tayside
Carol Colquhoun, National Screening Coordinator, NSD
Richard Copeland, Head of IM&T, NHS Greater Glasgow & Clyde
John Davies, SCAN Lead Cancer Clinician
Dominic Dick, Data Development Manager, ISD
Tom Divers, Chief Executive, NHS Greater Glasgow & Clyde
James Docherty, Consultant Surgeon, NHS Highland
Rachael Dunk, Team Leader, Cancer Strategies, Scottish Government
Stephen Gallagher, Head of Improvement & Support and Deputy Director of Health Delivery, Scottish Government
John Glennie, Chief Executive, NHS Borders
Jennifer Godsman, Cancer Audit Manager, NHS Highland
Kate Harley, Head of Programme, ISD
Jean Harvey, Cancer Definitions Manager, ISD
David Hill, Consultant Radiologist, NHS Dumfries & Galloway
Karen Jack, Cancer Audit Manager, NHS Tayside
Wilma Jack, Senior Clinical Research Fellow, NHS Lothian
Gary Jenkins, General Manager, Beatson West of Scotland Cancer Centre
Margaret Kelly, Cancer Services Manager, NHS Lanarkshire
Cath Lavery, New Cancer Waits IT Project Manager, ISD
David Linden, Programme Manager – Cancer Performance Support Team, Scottish Government
Cameron Martin, Consultant Gynaecological Oncologist, Royal Infirmary of Edinburgh
Tracy McKen, Policy Advisor (Screening), CMO & Public Health Directorate, Scottish Government
Sue McLaren, Cancer Pathway Lead, NHS Greater Glasgow & Clyde
Doug Main, Cancer Audit Administrator, NHS Fife
Sandra Mair, Director of Operations, NHS Lothian
Brian Murray, National Cancer Information Coordinator, ISD
Isobel Neil, Programme Director – Cancer Access, Scottish Government
Bill O'Neill, Chair Scottish Primary Care Cancer Group, NHS Lothian
Mary Orzel, Cancer Services Manager, NHS Forth Valley
Alison Pickering, Data Analyst, Cancer Performance Support Team, Scottish Government
Elizabeth Preston, Head of Service Cancer & Palliative Care, Edinburgh Cancer Centre
Tony Rafferty, Cancer Pathways Facilitator, NHS Grampian
David Rowley, Assistant Statistician, Health Finance Directorate, Scottish Government
Shirley-Anne Savage, Cancer Services Programme Manager, NHS Fife
Tom Sim, Business Support Manager for Cancer, NHS Lanarkshire
Robert Williams, Head of Performance and Business Management, Scottish Government
Stan Wright, Consultant Respiratory Physician, NHS Forth Valley