

Reporting of Quarterly Cancer Waiting Time Information (62 day treatment target)

Data Definitions and Guidance Document

Version 2.0 (May 2018)

Contents

Background	3
Definitions	4
Collection of Data	6
- Inclusions	
- Exclusions	
Reporting of Data	7
Data Validation	8
Data Use	9
Contact Details	10
Appendices	11

- Frequently Asked Questions
- List of variables collected from CaPPS

1 BACKGROUND

The Cancer Patient Pathway System (CaPPS) provides official monitoring of the Commissioning Plan Direction targets set by the Department of Health (DoH) in relation to the length of time a patient waited for cancer treatment following an urgent GP referral for suspect cancer.

Data used to report on the 62 target is derived from the Cancer Patient Pathway System (CaPPS), a bespoke data system used to administer cancer treatment services within Health and Social Care (HSC) Trusts in Northern Ireland. This dataset contains patient level information and enables the Department to report on the number of patients treated for cancer following a decision to treat being taken and by HSC Trust and tumour site.

Hospital Information Branch (HIB) introduced the collection of cancer waiting time information in April 2008. This was the first time such data were collected in Northern Ireland.

2 **DEFINITIONS**

DATE OF REFERRAL - This is the date on which a referral is received by the HSC Trust from a General Practitioner.

DATE OF FIRST DEFINITIVE TREATMENT - The date of the first definitive treatment is normally the date on which a first intervention which is intended to remove or shrink the tumour occurs (see Frequently Asked Questions).

COMPLETED WAITING TIME - is measured from the date an initial suspected urgent cancer referral is first received in a Provider Trust (the date on which the referral is date stamped, irrespective of the format in which the referral is received) and ends on the date that the patient received their first definitive treatment for cancer. The patient waiting time should be adjusted by removing the period of time for which they were suspended out of the overall waiting time (see Frequently Asked Questions).

SUSPENSIONS - a patient may be suspended from a waiting list for medical or social reasons. The patients waiting time should be adjusted by removing the period of time for which they were suspended out of the overall waiting time.

- (i) A patient can be suspended for social reasons:
 - 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).
- (ii) A patient can't be suspended for social reasons:
 - When a patient chooses a treatment with a longer waiting time (e.g. radiotherapy rather than surgery).
 - When 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.
- (iii) A patient can be suspended for medical reasons:
 - 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).

- (iv) A patient can't be suspended for medical reasons:
 - 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.
 - When 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.

3 COLLECTION OF DATA

INCLUSIONS

All urgent GP referrals for suspected cancer and any routine GP suspected cancer referrals that have subsequently been reclassified as urgent by a cancer specialist are covered by this target. An appointment with a cancer specialist is an appointment with a consultant, a member of his/her firm or locum, for such a member in respect of one referral. This target only applies to referrals that were initially referred by a GP.

Only patients that have received first definitive treatment for cancer in the month, having been given an ICD 10 diagnosis, are covered by this target.

Figures include all patients receiving treatment in an NHS hospital in Northern Ireland, including those patients living outside Northern Ireland and all privately funded patients waiting for treatment in NHS hospitals in Northern Ireland. In the event that a patient has been seen in the Independent Sector, the transferring Trust is responsible for reporting the completed wait of the patient in the applicable monthly return.

Waiting times must be reported for all cancers and be categorised by the following tumour sites; (Brain / Central Nervous System Cancer, Breast Cancer, Gynaecological cancer, Haematological malignancies (excluding acute leukaemia), Head and neck cancers, Lower gastrointestinal cancer, Lung Cancer, Sarcomas, Skin cancers, Upper gastrointestinal cancers, Urological cancers and Other suspected cancers

EXCLUSIONS

Referrals from sources other than a GP

Patients that have not been given an ICD 10 diagnosis

Patients that are currently suspended for medical and social reasons

All cases of basal cell carcinoma

4 REPORTING OF DATA

The HSC Business Services Organisation has developed a specific universe on the HSC Data Warehouse entitled 'CaPPS Test'. This universe is populated with data extracted directly from the Cancer Patient Pathway System (CaPPS) relating to patients who have received treatment following a decision to treat being taken.

HIB use a Business Objects query, agreed with HSC Trusts and the HSC Board, to extract anonymous patient level data from this universe two months after the end of each quarter.

This information is exported into a statistical software package called SPSS where it is cleansed and analysed to ensure that only patients that were treated during each month of the quarter in question and that meet the criteria outlined in Section 3 are included.

Following the validation procedures, outlined in Section 5, data are marked as final and are published in the Northern Ireland Waiting List Statistics: Cancer Waiting Times publication.

The Dataset contains a range of variables enabling waiting times for cancer treatment following an urgent GP referral for suspect cancer to be published on the basis of:

HSC Trust – the Trust responsible for the management of the patients waiting time;

Tumour Site – the primary tumour site for which the patient has received treatment;

Length of time waiting – the length of time between the date the HSC Trust received the urgent GP referral for suspect cancer and the date of first definitive treatment.

5 DATA VALIDATION

HIB perform a two stage validation of the 62 day waiting time data extracted each quarter.

STAGE 1

Following extraction of the 62 day completed waits for the relevant quarter from the 'CaPPS Tests' universe on the HSC Data Warehouse, HIB circulate an excel workbook to each HSC Trust outlining:

- Number of patients waiting under and over 62 days for each of the three months, and the % waiting under the target.
- A patient level list of 62 day breachers.
- A list of all patients recorded as having breached the 62 day waiting time target;
- Any duplicate cases, either within the HSC Trust, or between HSC Trusts. Where the duplicates are between HSC Trusts both Trusts are sent the relevant details.
- Cases where erroneous dates are recorded for either GP referral or date first seen.
- Cases where there is no ICD10 diagnosis, hospital first seen or provider of first treatment documented.

HSC Trusts validate these data and confirm correct figures.

STAGE 2

Amendments are made by the HSC Trusts on CaPPS, as required, in response to the Stage 1 Validation. HIB repeat the extraction and ensure the final number of patients waiting under and over 62 days for each of the three months, and the % waiting under the target match what HSC Trusts have confirmed.

7 DATA USE

Data contained within the Cancer Patient Pathway System (CaPPS), are classified as National Statistics.

These data are published on a quarterly basis in the Northern Ireland Waiting Time Statistics: Cancer Waiting Time publication. The most recent publication, together with previous editions, can be found at the following link:

https://www.health-ni.gov.uk/articles/cancer-waiting-times

Cancer waiting time data are also used in:

- Ministerial answers to both Written and Oral Assembly questions;
- Departmental responses to correspondence received from the NI Assembly Health Committee, Public Accounts Committee, Northern Ireland Audit Office and other stakeholder bodies such as the Patient Client Council;
- Ministerial briefing material;
- Health compendium publications, and
- Responses to data requests from the HSC, politicians, journalists, voluntary / charitable organisations and members of the general public.

8 CONTACT DETAILS

This document will be reviewed and updated periodically.

If you have any issues relating to the contents of the document or the collection of cancer waiting time information in general please contact:

Hospital Information Branch Information and Analysis Directorate Department of Health Stormont Estate Belfast BT4 3SQ

E-mail: statistics@health-ni.gov.uk

APPENDIX 1: FREQUENTLY ASKED QUESTIONS

Q1. At least 95% of patients urgently referred with a suspected cancer should begin their first definitive treatment within 62 days of the referral being received. Is this 62 calendar days or 62 working days?

62 days refers to 62 calendar days. This 62 day period includes weekends and bank/public holidays.

Q2. What are the first definitive treatment options?

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 as a first definitive treatment for these purposes. In more detail:

First definitive	Circumstances where this applies
treatment type	
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,	 Chemotherapy (including cases where this is being given prior to planned surgery or radiotherapy)
Biological therapy+ OR Hormone therapy	◆ 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
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 (if known by the Trust)

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.

Q3 What is the start date for the first definitive treatment?

First definitive treatment type	Defined start date
Surgery	Date where the procedure took place with the patient as an admitted patient – either as an in-patient or as a day case. Record the date of admission for the hospital stay during which this procedure took place.
Chemotherapy and/or other anti-cancer treatment	Record the date on which the first dose of the drug is administered to the patient.
Hormone therapy and/or treatment (including hormone/endocrine therapy and immunotherapy)	Record the date on which the first dose of the drug is administered to the patient.
Brachytherapy	Record the date on which the first fraction of brachytherapy for this prescription is administered to the patient.
Radiotherapy/ Teletherapy	Record the date on which the first fraction of radiotherapy for this prescription is administered to the patient.
Specialist Palliative Care	Record the date of the first treatment/support from specialist palliative care.
Active monitoring	Record the date of the consultation on which this plan of care was agreed with the patient. This only applies to prostate cancer.

Q4. Waiting time targets should be reported for which Tumour sites?

The waiting times from date of receipt of GP referral to date of first definitive treatment must be reported for all cancers and categorized by the following tumour sites:

- Brain / Central Nervous System Cancer
- Breast Cancer
- Gynaecological cancer
- Haematological malignancies (excluding acute leukaemia)
- Head and neck cancers
- Lower gastrointestinal cancer
- Lung Cancer
- Sarcomas
- Skin cancers
- Upper gastrointestinal cancers
- Urological cancers
- Other suspected cancers

Q5. When patients are initially referred to a particular Trust and are subsequently sent on to another Trust for treatment – which Trust has the responsibility for reporting on the 62 day wait?

There is shared responsibility for patients in the 62-day target between the Trusts were a patient was first seen and the Trust was the patient was first treated.

Initial responsibility lies with the Trust were the patient was first seen to refer the patient in a timely manner to the treating Trust allowing the treating trust adequate time to plan the treatment and deliver the diagnostic investigations in an appropriate timeframe to enable the target to be met.

Any breaches of the 62 day target will be count half for both the Trust to which the patient was first referred and half to the Trust was treated. Where a 62 day breach occurs a discussion must take place between referring and treating trusts and agreement reached as to the reason for the breach.

APPENDIX 2: LIST OF VARIABLES COLLECTED FROM CaPPS

Variable Name	Variable Description
Episode ID	Unique identifier for patient episode
'HCN'	Patient's Health and Care Number
Trust First Seen	Name of Trust in which the patient is first seen
Trust First Treated	Name of Trust in which the patient receives their
	first treatment.
Suspected Tumour Site	Suspect Tumour site Code
Suspected Tumour Site -	Suspect Tumour site Description
Description	
Casenote	Patient Casenote Number
Cancer Referral Type Description	Cancer Referral Type Description
Confirmed Tumour Site	Primary tumour site (based on ICD10 diagnosis)
62 Day Under Target	Indicates whether patient received first treatment
	within 62 days
62 Day Over Target	Indicates whether patient waited over 62 days for
	first treatment
Urgent Cancer Referral Type Code	Code of urgent cancer referral
Urgent Cancer Referral Type	Site where cancer is suspected by the GP or
District Toronto	GDP or Consultant
Priority Type Code	Code of priority type
Primary Referral Date	Date on which primary referral request received
Consultant Deferred to	by provider Consultant responsible for the care of the nations
Consultant Referred to Date First Seen	Consultant responsible for the care of the patient Date of first attendance with consultant
Date Treatment Planned	Date of planned first treatment
Date Decision to Treat	Date on which decision to treat taken
First Treatment Date	Date that the patient receives their first treatment.
Cancer Status	Description of cancer status
Cancer Status Code	Code of cancer status
Hospital First Seen	Name of hospital in which patient is first seen
Hospital First Treated	Name of hospital in which patient is first treated
First Treatment Type	Type of first definitive treatment
Final Waits 62 Days	Final adjusted waiting time for 62 day target
Diagnosis Code	Primary ICD 10 diagnosis
Diagnosis	Description of primary tumour site (based on
	ICD10 diagnosis)
62Day Trust - Completed Waits	Trust for which the under and over target values
	are calculated