Department of
# Health
An Roinn Sláinte

Männystrie O Poustie

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# Reporting of Quarterly Cancer Waiting Time Information (31 day treatment target)

# Data Definitions and Guidance Document

# Version 2.0
# (May 2018)

# Contents

# 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 a decision to treat being taken.

Data used to report on the 31 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

**DECISION TO TREAT -** Decision to treat date is the date on which it was decided that the patient should receive treatment for cancer. This is the date that the consultation between the patient and the clinician took place and a treatment plan was agreed.

**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).

**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**
Only patients that have received first definitive treatment for cancer in the month and that have an official ICD 10 diagnosis are covered by this target.

All patients who have received their first definitive treatment for cancer during the month, with an ICD 10 diagnosis, irrespective of the source of referral (i.e including those that weren't referred by a GP for suspected cancer). All initial referrals from the following sources are included in the target:

- General Practitioner / General Dental Practitioner
- Accident and Emergency Department
- Other consultant (other than A & E Dept)
- Self-referral
- Prosthetist
- Another Health Practitioner
- Family Planning Service
- Voluntary Agency
- Criminal Justice Agency
- Screening Service
- Following ICATS triage at any stage of the patient pathway i.e. triage, diagnostic, Tier 2 appointment etc
- Other source of referral

Patients who weren't initially referred for cancer but were diagnosed with cancer 'incidentally' following routine investigations or diagnosed following treatment for another condition are included.

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 on the Cancer Waiting Times Database.

Waiting times must be reported for all cancers and 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, Other suspected cancers.

**EXCLUSIONS**
Patients who have not been given an ICD 10 diagnosis.

Patients who are currently suspended for medically or socially 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 a decision to treat being taken 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 decision to treat being taken and the date of first definitive treatment.

# 5    DATA VALIDATION

HIB perform a two stage validation of the 31 day waiting time data extracted each quarter.

**STAGE 1**

Following extraction of the 31 day completed waits for the relevant quarter from the 'CaPPS Test' universe on the HSC Data Warehouse, HIB circulate an excel workbook to each HSC Trust outlining:

- Number of patients waiting under and over 31 days for each of the three months, and the % waiting under the target.

- A patient level list of 31 day breachers.

- A list of all patients recorded as having breached the 31 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 or provider of first treatment documented.

- Number of patients waiting under and over 31 days for each of the three months for each confirmed tumour site.

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 31 days for each of the three month, 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
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## APPENDIX 1: FREQUENTLY ASKED QUESTIONS

**Q1. At least 95% of patients diagnosed with cancer should begin their first definitive treatment within 31 days of the decision to treat date.  Is this 31 calendar days or 31 working days?**

31 days refers to 31 calendar days. This 31 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 treatment type | Circumstances where this applies |
|---|---|
| **Surgery** | ♦ Complete excision of a tumour<br>♦ Partial excision/debulking of a tumour (but not just a biopsy for diagnostic or staging purposes)<br>♦ 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<br>(1) Where hormone treatment is being given as the sole treatment modality<br>(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<br>♦ Given via community SPC teams<br>♦ 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.<br>♦ 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. How should patients who have been diagnosed with cancer 'incidentally' be recorded?**

Some patients may be diagnosed for cancer during routine investigations or while being treated for another condition. This is why the target monitors the waiting time from decision to treat to first definitive treatment. Once cancer is diagnosed the patient should be treated without delay and 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 intervention. (e.g. when a patient is unexpectedly found to have a cancer during surgery for a suspected benign condition).

## 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 - Description | Suspect Tumour site Description |
| Casenote | Patient Casenote Number |
| Cancer Referral Type Description | Cancer Referral Type Description |
| Confirmed Tumour Site | Primary tumour site (based on ICD10 diagnosis) |
| 31 Day Under Target | Indicates whether patient received first treatment within 31 days |
| 31 Day Over Target | Indicates whether patient waited over 31 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 GDP or Consultant |
| Priority Type Code | Code of priority type |
| Primary Referral Date | Date on which primary referral request received by provider |
| Consultant Referred to | Consultant responsible for the care of the patient |
| Date First Seen | 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 31 Days | Final adjusted waiting time for 31 day target |
| Diagnosis Code | Primary ICD 10 diagnosis |
| Diagnosis | Description of primary tumour site (based on ICD10 diagnosis) |