

Questions answered by NCAT – December 2009

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Two Week Wait (2ww)

GPs often don't tell the patient that they are being referred with a possible cancer, which makes conversations about the urgency of their appt very difficult. We contact the GP to inform them that the patient is not making themselves available and ask that the GP discuss this with the patient. Depending on the outcome of that discussion the patient is either rebooked or discharged back to GP. Is this arrangement acceptable given that there is discussion with the patient albeit by a primary care rather than secondary care clinician?

I have discussed this briefly with DH and they do not see why this would be a problem if the GP is the appropriate clinician to have the discussion with the patient. However, they did note that this would need to be part of an agreed protocol between primary and secondary care. Both DH and NCAT were unsure how the logistics of this would work in practice ie. would a GP be prepared to have this pro-active conversation, would they want additional payment for this task, would they remember to tell you when this had happened, how would you chase if you hadn't heard etc. In summary, the approach seemed acceptable within clear protocols but not without logistical issues.

Can a 2ww referral be made from an independent sector Clinical Assessment Service (CAS)?

Yes if they are acting on behalf of a patient's GP (but locally agreed guidelines would need to be in place to support this) and the activity at the private CAS has been commissioned by the NHS.

You have advised that a patient can be discharged back to the GP after multiple appt cancellations as long as the patient agrees. These multiple cancellations can go on for months. Is there a plan to draw a line limiting the number of cancellations a patient can make or the length of time they can postpone their OPA before they are referred back to their GP who can reassess if the problem remains/has worsened?

No, this is being left for local policy.

Symptomatic breast 2ww

If 2WW breast symptomatic patients have been put on the system from before the service was commissioned - should these then be removed or does it not matter as it is only a standard from 1 January 2010 onwards?

I would be pragmatic and say it doesn't matter.

We have been informed by one of our Trusts that if a Trust fails to meet the operational standard for either the breast symptomatic 2ww or the breast cancer 2ww, then the CQC will fail them on both. Is this true?

You should check on the CQC website to see details of their indicator constructions.

What is the position for patients self referring after an open discharge – how should self-referrals be recorded?

Self referral is an acceptable route for the symptomatic breast 2ww. I have confirmed with DH that these patients would therefore be on the symptomatic breast 2ww pathway unless this is part of an agreed follow up protocol in which case it would not be necessary to include them.

Following treatment and open discharge a patient self refers back to the Breast unit, the patient is seen in the unit and:

a) just reassured that they do not have a recurrence - do we need to record this?

Yes – record for symptomatic 2ww only

b) a recurrence of the previous cancer is found – how do we record this?

The patient would be covered by the Symptomatic breast 2ww standard and once a recurrence is confirmed they would then be covered by the subsequent 31d standard.

c) a new cancer is found – how do we record this?

The patient would be covered by the symptomatic 2ww standard and, as this is a new standard, they would also be covered by the 62 day standard.

You have advised that a patient can be discharged back to the GP after multiple appt cancellations as long as the patient agrees. These multiple cancellations can go on for months. Is there a plan to draw a line limiting the number of cancellations a patient can make or the length of time they can postpone their OPA before they are referred back to their GP who can reassess if the problem remains/has worsened?

No, this is being left for local policy.

A symptomatic breast 2ww patient may not feel a sense of urgency about their appointment. We contact the GP to inform them that the patient is not making themselves available and ask that the GP discuss this with the patient. Depending on the outcome of that discussion the patient is either rebooked or discharged back to GP. Is this arrangement acceptable given that there is discussion with the patient albeit by a primary care rather than secondary care clinician?

I have discussed this briefly with DH and they do not see why this would be a problem if the GP is the appropriate clinician to have the discussion with the patient. However, they did note that this would need to be part of an agreed protocol between primary and secondary care. Both DH and NCAT were unsure how the logistics of this would work in practice ie. would a GP be prepared to have this pro-active conversation, would they want additional payment for this task, would they remember to tell you when this had happened, how would you chase if you hadn't heard etc. In summary, the approach seemed acceptable within clear protocols but not without logistical issues.

Are there any plans to review the 93% tolerance for the symptomatic breast standard based on the data uploaded prior to 1 January 2010?

DH will be keeping the operational tolerances for all the standards under review but I don't think the info collected on breast 2ww prior to go live would be of sufficient quality for DH to make decisions based on. *DH Advice: The Department of Health has no immediate plans to review this operational standard based on data currently available. As such we will be expecting performance to be compliant with this standard for patients seen after 31 December 2009.*

A GP suspected cancer referral cannot be sent back to a GP after a 1st DNA). Does this apply to the TWW breast symptomatic referrals too?

Yes it applies to the symptomatic breast 2ww too.

If a patient enters the system as a breast symptom referral, is then found to have a cancer and breaches the 62 day target, will this be included within the 62 day classic report before the end of December 09?

The symptomatic breast 62d is a separate cohort to the 62d classic.

The 62d symptomatic breast standard will go live from 1 Jan 2010 i.e. the same as the symptomatic breast 2ww standard. However, the 62d symptomatic breast standard is not being monitored centrally for the time being - DH is focusing on the cancer waits standards in the vital signs at the present time. We would, however, expect you to be keeping check on performance for this standard locally. DH will be including reports to help with this in the report suite available on the CWT-Db in due course.

31d treatment (first or subsequent)

If a patient needs surgery but this cannot be delivered within 31 days and we get them to agree to active monitoring in the interim is that acceptable?

It is my view that you would be seeking to use active monitoring inappropriately in the above scenario ie as a means to stop the clock earlier.

Active monitoring is where a diagnosis has been reached but it is NOT appropriate to give any active treatment at that point in time but an active treatment is still intended so the patient is monitored until a point in time when they are fit to receive or it is appropriate to give an active treatment. If a patient needs time to think about the treatment options they have been presented with then that is thinking time NOT active monitoring and if a Trust does not have capacity to deliver treatment in a timely manner that is not a reason for active monitoring.

For example: active monitoring is a legitimate treatment option where the decision had been taken to monitor the progress of a specific condition for example a slow growing cancer where there is not an immediate problem and it is clinically appropriate to step back and monitor the situation until an active intervention is more appropriate. It is not appropriate if a patient has been presented with a number of treatment options eg open or lap prostatectomy or brachytherapy and they want to take some time to consider this or they have agreed to a type of treatment but there is a long waiting list.

DH has reviewed the operational tolerances and, for example, changed the 31d FDT from 98% to 96% to take into account that more patients will either choose to wait longer than 31d or will not be fit enough to be treated within that timeframe.

Some patients need to have a special diet for a month before they can undergo radio-iodine treatment – is this classed as an enabling treatment?

No. The majority of enabling treatments would have been medical suspensions under the old system of counting waits. These have now been taken into account with a lower tolerance.

Would an ECAD be appropriate for patients who won't be physically able to have a radioiodine treatment without a special diet beforehand?

I have discussed this briefly with my colleague at DH we have agreed that I need to seek clinical advice on this. In particular I need to get a sense of how often this treatment is used (do you know which tumour types it is most relevant to?) and what proportion of patients need a month long diet etc etc. We can then decide how this should be managed within the cwt rules. The ECAD relates to the next ACTIVITY that actively progresses a patient pathway and until we have further advice DH and NCAT have agreed that this would be when the patient and consultant agree that they are fit to start the diet (ie. they might be able to start the diet while convalescing from surgery etc).

How long should be allowed for 'thinking time' before a patient is given a status of 'Active Monitoring?'

There is no definitive answer for this. The position is the same as for 18 weeks ie. it depends on the individual scenario. The 18 weeks guidance advises that if the agreed "thinking time" is short, then the 18 week clock should continue to tick (eg. where invasive surgery is offered as the proposed first definitive treatment but the patient would like a few days to consider this before confirming they wish to go ahead with the surgery). If a longer period of "thinking time" is agreed, then active monitoring is more appropriate (eg. where the patient and clinician agree that the patient's symptoms are not severe at the moment and so the patient does not want surgery at this stage and a review appointment is agreed for 3 months time). It is my view that active monitoring is NOT a substitute for 'thinking time'.

A patient had no time frame put on them to make a decision on treatment and waited over 100 days before deciding that they wanted to try surgery - is that active monitoring in the interim?

No. The patient would have had to agree that they were choosing to be actively monitored for a period of time rather than have active treatment. In your scenario that would not appear to be the case.

If a patient keeps going from one consultant to another to discuss options, i.e. surgeon, then oncologist, then back to a different surgeon etc – is that active monitoring as they will be monitored between visits?

This is not active monitoring as a DTT has yet to be reached.

Are active monitoring and clinical follow-up one and the same thing?

No

When cancer patients decline any treatments and would rather follow-up by their local GPs and nurses, will this be classed as active monitoring?

No. There is an option under cancer treatment modality for all treatment declined (code 98).

November's Q & A stated Specialist Palliative Care is palliative care delivered under the management of a consultant in palliative medicine – can you clarify if SPC can be given via hospital SPC teams, community SPC teams and hospices?

As I said, it is pally care delivered under management of a consultant in pally medicine - if that is the case in these 3 scenarios then yes though for hospices you would record the date referred to them.

Can you elaborate on Non -specialist Palliative Care - would that be via Macmillan nurses or any other specialists say GPs and Oncologists?

As I said it is pally care delivered under management of a consultant other than one specialising in pally medicine - in your scenario it is unlikely to be a nurse but could be an oncologist. Not sure if a GP is classed as a consultant or not.

Are patients treated with bisphosphonates reported as part of the GFOCW standards? My inclination is that they should not as this treatment is given to help to strengthen the bones and reduce the risk of fractures or breaks rather than to treat the cancer itself? Can you advise?.

I'm minded to agree with you so I suggest you exclude them for now.

if chemorad is the treatment would the Trust who is providing the chemotherapy or the radiotherapy report the treatment?

Chemorad is a treatment option in its own right [CANCER TREATMENT MODALITY code 04] and if the chemo part is delivered first then this is the bit that would stop the clock and vice versa – the trusts commissioned to provide the treatment in question would report it..

Regarding inpatient chemotherapy or radiotherapy should the clock not stop on admission rather than first fraction/dose. The 18 weeks guidance states that the clock stops on admission for treatment. If the cancer clock is stopped on the first fraction/dosage then there will be a discrepancy between the cancer pathway and the 18 week.

I have checked with DH and they have confirmed that for cancer waits the date of admission only stops the clock for surgery. We use date of first fraction/dose etc for r/t and chemo so that we have the same starting point whether r/t/chemo are undertaken as admitted or non-admitted care. DH acknowledge that this differs slightly from 18w.

Classic 62d (ie. from 2ww)

My understanding is that if a 2WW referral is received for Head & Neck but the patient's care is then internally referred to the Lung team but treatment does not take place until after the 62 treatment target date then the breach is allocated to the H&N team because that is where the referral originated. Is that true?

The 2ww would remain a suspected head & neck but the 62d would use the ICD10 code for the diagnosis i.e. lung. In terms of breach allocation it rests with providers/trusts not individual teams i.e. a breach rests with the provider commissioned to provide DATE FIRST SEEN and provider commissioned to provide treatment.

A patient has been referred in (2ww) and is a possible cancer. However it has not been possible to confirm that there is a cancer or rule it out definitely and so it has been decided to monitor the patient on a 6 monthly basis. If at a later stage cancer is confirmed, when would the pathway commence?

If this is a 2ww patient the pathway would start at receipt of original 2ww referral and the clock would continue to tick until the patient is told they do not have cancer or are told they do have cancer and are then treated. If a patient cannot be given a diagnosis due to clinical uncertainty the clock keeps ticking and the patient will breach but the tolerance has taken into account that there will be a proportion of patients in this category.

We have a GP fast track patient who first presented with hepatic metastatic sigmoid adenocarcinoma whose treatment plan was to have upfront hepatic surgery (as it was considered that if the liver mets were to increase in size any further this may make the disease inoperable), followed by removal of their primary colonic cancer 2 weeks later. The tertiary Trust who performed the liver resection believes that this surgery should be considered as a separate subsequent treatment of a met and that the colonic surgery should be the first treatment recorded. Is this correct?

The tertiary centre is correct. Treatment of mets is always classed as a subsequent treatment (unless it is treating mets of unknown origin). Therefore in your scenario the colonic surgery would be the first definitive treatment for the primary cancer (and thus stop the 62d clock). It does not matter that the treatment for the mets took place first as the 31d records for first and subsequent treatments don't need to be uploaded sequentially. Some people have queried the policy decision that treatment of the mets cannot be classed as the FDT and DH will consider this further but at the present time the position is as I have set out. Under the old system a medical suspension would have been allowed for calculating the time to FDT. Under the new system the operational tolerance has been lowered to take into account that more patients will breach the standard because they choose to wait longer or are not clinically able to be treated within that time.

31d rare cancer

If there is a patient referred as a Urology 2ww (non testicular) who is later diagnosed with a testicular tumour, are they counted under the 62d or 31d rare tumour pathway given their entry route? They are showing on our preview report for rare cancers.

Patients are shown in the report relevant to what they are ultimately diagnosed with, as determined by ICD-10 coding. Therefore a patient referred via a urology two week wait subsequently diagnosed with cancer will be in the rare cancer report.

If a patient is referred in as a general 2ww appointment they are on a 62 day pathway, but by putting them into the rare cancers section they are showing as a 31 day breach, even though they met the 62 day standard. Do you think this is correct?

The policy on the accelerated 31-day standard has been in place since before the inception of the Cancer Waiting Times Database, there has always been a potential issue with, for example, the haematological malignancies in that the differentiation between acute leukaemia and other forms may not happen until the pathway has commenced. However we have no plans to alter the way patients are monitored for this standard. I would also point out that these patients are not assessed individually within Vital Signs due to small numbers, this means that whilst the published national statistics will identify a failure against the 31-day standard, the provider and it's commissioning PCT will not be penalised for any uncertainty in the GP referral.

62d upgrade

A patient has been referred in and is upgraded with a possible cancer. However it has not been possible to confirm that there is a cancer or rule it out definitely and so it has been decided to monitor the patient on a 6 monthly basis. If at a later stage cancer is confirmed, when would the pathway commence?

For an upgrade the clock starts at the decision to upgrade and the clock would continue to tick until the patient is told they do not have cancer or until they are told they do and have their first treatment. No tolerance has been set at a national level for this standard at the present time. The 62d upgrade records are not uploaded until a patient is treated for cancer.

62d Screening

If a patient is referred in as a breast screening patient, but then is found to have a lymphoma, they are showing as a lymphoma pt under the screening report? Is this accurate?

Patients are included in the screening 62-day report if they are urgently referred from a screening service. A lymphoma patients could be identified in this report if the urgent referral came from an NHS screening service.

Is it likely that Trusts with small screening numbers will be excluded from the CQC ratings for the 62d screening standard?

The Care Quality Commission (CQC) do normally publish and apply a de minimis limit within their annual assessment process. Therefore it is reasonable to assume that any analysis incorporating this dataset will also be subject to such restrictions. Due to the independent nature of the CQC I cannot comment on what such a limit might be, however you might wish to address a query on this matter to: Performance.Indicators@cqc.org.uk.

Do you have any advice you could pass on to clinical teams with regards to meeting the colorectal screening measure as this is a measure that teams are finding particularly difficult?

I would suggest that teams look at v6.5 of the GFOCW in the first instance - part 3 includes a section specifically on 62d for patients urgently referred from the bowel screening programme. In terms of data, DH has recently provided the following summary:

'All activity on this pathway is shared between the provider where the patient is seen by the nurse practitioner who assesses suitability for colonoscopy (usually the screening service host) and the provider where the first definitive treatment is given. For entering these data onto the CWT-Db the key events dates to be captured are:

- *the date of the referral to the nurse practitioner led assessment clinic (CANCER REFERRAL TO TREATMENT PERIOD START DATE);*
- *the date of the appointment with the nurse practitioner to assess suitability for colonoscopy (DATE FIRST SEEN);*
- *the date of any subsequent decision to treat date (CANCER TREATMENT PERIOD START DATE); and*
- *the date of the first definitive treatment (TREATMENT START DATE (CANCER)).*

All of these fields must be present in the same CWT-Db record, with related organisation codes for the activity to be correctly shared between organisations.'

Is it possible to confirm from Q2 data that all Trust's who are the commissioned provider for Bowel Screening services are reporting cancer screening activity accurately?

Not at a national level. DH has been doing some work on data completeness but this is not one of the standards that is a priority for this work. At the end of the day DH would rely on Trusts, PCTs and SHAs to ensure that all the necessary data is being collected and uploaded correctly.

Pauses

Provider A has a patient who needs radiotherapy, they could offer this within the standard time. However the patient is choosing to delay until after the New Year – can an adjust be made even though this will be an outpatient treatment?

The only adjustment is if the patient declines a reasonable appt for admitted treatment. If the r/t was in-patient or day case then a pause would be possible but if it was outpatient then no adjustment would be possible. DH have revised the operational tolerances to take into account that more people will choose to wait longer than the standard times.

We have a 2WW lung patient who was seen well within 14 days and has then been sent for a tspot test. He has DNA'd this test twice but we have offered him another appointment – is a pause allowed for this DNA of diagnostics?

There are no pauses for DNAs at the diagnostic stage but if a patient multiple DNAs any appt (2 or more) you can (if it is your local policy) refer them back to their GP. As you have offered a 3rd appt (and I assume the patient has accepted it) you could consider this action if they DNA this appt.

Is there a national description of what can/can't be recorded as a complex diagnostic pathway?

Not that I am aware of. I would take it as anything that is significantly different from the norm for the tumour in question.

Breaches

We are not the host trust for the bowel screening service but patients are booked here for colonoscopy & onward treatment depending on where they wish to be treated. Up until now we have taken the full hit for any bowel screening patient breaches wherever they occur but I have been told that other Trusts share the screening breaches with the screening service (or their host trust). Is this correct?

Advice from DH: All activity on this pathway is shared between the provider where the patient is seen by the nurse practitioner who assesses suitability for colonoscopy (usually the screening service host) and the provider where the first definitive treatment is given.

For entering these data onto the CWT-Db the key events dates to be captured are:

- *the date of the referral to the nurse practitioner led assessment clinic (CANCER REFERRAL TO TREATMENT PERIOD START DATE);*
- *the date of the appointment with the nurse practitioner to assess suitability for colonoscopy (DATE FIRST SEEN);*
- *the date of any subsequent decision to treat date (CANCER TREATMENT PERIOD START DATE); and*
- *the date of the first definitive treatment (TREATMENT START DATE (CANCER)).*

All of these fields must be present in the same CWT-Db record, with related organisation codes for the activity to be correctly shared between organisations.

X Cancer Networks have agreed to a policy which precludes the sharing of breaches of the 62 day pathway if the patient was referred to the treating Provider organisation on or after day A of the patient pathway where the reason for the breach was administration error, or where administration error was a factor. Is this acceptable?

There is nothing to stop networks agreeing local protocols to try to improve timeliness of referral processes locally. However, the terms of this local agreement would NOT supercede the DH or CQC reallocation policies. I know that some Trusts asked the CQC earlier in the year if they would be prepared to accept a locally agreed reallocation policy over and above their national policy - CQC decided against this at the time and I am not aware that this position has changed.

I have been asked about information sharing for breaches where there has been an admin error and if they are returned back to the originating trust – is there a policy on this?

The breach reallocation policy is the CQC's so you would need to go to their website - I think you will find it at: www.cqc.org.uk/db/documents/reallocation_form_200904291418.doc

Performance management

What was the methodology DH used for their symptomatic 2 week wait ready reckoner?

- *The numbers of all the patients who were treated for cancer at each provider without being referred under the two week wait since April 2007 are entered into the analysis (these data are in DSCN 22/2002 format);*
- *An average number of cases of this type per quarter is calculated for each organisation;*
- *This is adjusted to exclude the normal proportion of breast cancer patients treated who are initially referred from NHS cancer screening services to each organisation (this is a local not national assumption based on DSCN 20/2008 data);*
- *This number of cancer treatments following referrals other than screening or cancer two week wait is then multiplied by 15, this reflects the national assumption on the conversion rate (ie. proportion of breast cancers expected to be diagnosed from referrals);*
- *This quarterly figure is divided by three to get a generic month, and rounded to the nearest ten cases to reduce the sensitivity of the model; and*
- *The ready reckoner is finalised.*

The caveats to this model are:

- *The model is based around the providers that treat the patients, therefore if a unit offers outpatient services, but no treatments a ready reckoner will not be calculated. These providers are identified as "no data to calculate" in the ready reckoner column of the table shared with SHAs. However, if the analysis is aggregated on a geographical basis the activity estimate should be reasonable. This treatment site basis may cause units to be given substantially lower estimates than normal, and vice versa for local centres;*
- *The ready reckoner uses a national assumption on conversion rates, however, breast services are significantly impacted by age as breast cancer is predominantly a disease of older women. To account for this the pass/fail conditional formatting is set at 75%;*
- *This model uses the Q1 2008/10 62-day screening data to part define the patient cohort to apply the conversion rate to, any under reporting in this area will degrade the accuracy of the analysis; and*
- *This model is degraded in its accuracy by any service reconfigurations within the last two years*

Will Trusts with small screening numbers be excluded from the CQC ratings?

DH advise: 'The Care Quality Commission (CQC) do normally publish and apply a de minimis limit within their annual assessment process. Therefore it is reasonable to assume that any analysis incorporating this dataset will also be subject to such restrictions. Due to the independent nature of the CQC I cannot comment on what such a limit might be, however you might wish to address a query on this matter to: Performance.Indicators@cqc.org.uk '.

Have CQC decided what they are doing with Q1 figures for their monitoring purposes?

The CQC have set out how they plan to use the data - this is on their website. From memory they plan to use all 4 quarters of data for all standards except the symptomatic breast 2ww where I think they only plan to use Q4.

Dataset

Cancer Treatment Modality

We have a patient who is going for radio-iodine as a subsequent treatment. How is this treatment recorded?

The **CANCER TREATMENT MODALITY** field does not yet have radioisotope therapies listed so you would need to code it as 'other treatment'

CWTDb

We have been looking at breaches and breach reasons for the 62 day pathway and it has come to our attention that what the Network download from Open Exeter is different to what the Trusts can download. In particular, we cannot see the breach reason, which I understand is selected by using a drop down list when the data is uploaded - we can only see the “delay reason comment”. Also we cannot see the “waiting time adjustment reason”. It would be helpful if we could see these - is there a possibility that this can change?

As I understand it there is no such report available for networks although you could get this info by downloading the anonymised patient records. If you think such reports would be valuable you can raise a change request with the OE helpdesk. DH will then consider and prioritise suggested changes to the system although they will not be in a position to assess such requests until the core functionality of the CWT-Db is complete.

For reports 2.2 and 2.8, 31 day standard and subsequent treatment standard by treatment type, it does not allow you to view the first seen and first treatment provider. The data shows that some of our Trusts, who do not provide radiotherapy, have got patients against radiotherapy as the treatment type. Is there duplication in this data? I.e. the treating trust reporting the patient having radiotherapy and the first seen provider reporting the (same) patient as having radiotherapy, even though not provided at that Trust?

Radiotherapy reports are not just for conventional r/t they also include patients having brachytherapy, proton or chemorad. So for chemorad for example, if the chemo was given first the chemorad would be recorded against the trust giving the chemo even though the r/t could be at a different trust. This might answer your query. It is also possible that incorrect provider codes have been entered.

For reports 3.2, the 62 day standard by treatment type, some of our Trusts who do not provide radiotherapy as treatment have got data that states they have treated patients with radiotherapy (as first treatment provider). This is clearly not right – please advise.

Radiotherapy reports are not just for conventional r/t they also include patients having brachytherapy, proton or chemorad. So for chemorad for example, if the chemo was given first the chemorad would be recorded against the trust giving the chemo even though the r/t could be at a different trust. This might answer your query. It is also possible that incorrect provider codes have been entered.

For report 3.7, the rare cancer standard, is downloaded by selecting the “62 day” report type, but when you select the report number, it is titled “Cancer Plan 31 Day Rare Cancer Standard”. Is this an error?

I suggest you report this to the OE helpdesk.

If a patient from X Trust is discussed at an X Trust MDT with a consultant from Y trust present, then the patient sees the Y Trust consultant in a clinic that afternoon which is held in X Trust and a Decision to Treat is made and the treatment will be carried out at Y Trust - who uploads the DTT and what Org code is to be used?

The key is the commissioning arrangements - the organisation that is commissioned to provide the treatment is responsible for ensuring that the DTT is uploaded and it would be their organisation code that would be used. A different provider can upload the DTT data for them using the NHS number/PPI etc to ensure the correct record is updated but it remains the treating provider's responsibility to ensure this data record is complete and it is their code that should be used.

Is there a user manual for Open Exeter Cancer Waiting Times that I can download?

Yes - go to the CfH website (link as follows: <http://nww.connectingforhealth.nhs.uk/nhais/cancerwaiting/documentation>). You will find a user manual for the cwtdb there. You will also find behavioural guidance (see v6.5) which explains about the standards and how to measure them etc.

Tumour-specific

Bladder

If a patient is urgently referred with a suspected testicular cancer (and is therefore on a 31d pathway) but is then diagnosed with a bladder cancer would they remain on a 31d pathway or be on a 62d pathway?

They would be on a 62d pathway because the 62d pathway is linked to the diagnosed cancer.

Gynae

We have a patient who has been diagnosed with vulval cancer and has had first treatment (surgery) but has now been listed for a bilateral groin node dissection to prevent further spread of the cancer (nodes were negative at original pathology). Should this be classed as a subsequent treatment as it is to prevent spread but not to treat the cancer itself, or, because the nodes are negative would this be excluded?

I would class this as a 31d subsequent treatment as the clinical team has decided that this procedure is necessary as part of the patient's treatment package to minimise risk of recurrence etc.

Haematology

We are having problems with subsequent treatments - the problem being that patients have so many treatments we are unsure what constitutes a subsequent treatment and what treatments should be grouped together?

Each COURSE of chemo is counted as a subsequent treatment. Where there are changes in drug type or combo we need to be pragmatic ie if it was decided to change the drug mix but the treatment carried on uninterrupted I wouldn't class that as a subsequent treatment. The GFOCW advisory board advised that the key would be whether a new consent form had been signed or not ie. if it has then it should be classed as a new treatment and therefore a new 31d period.

Scenario 1 - A patient is diagnosed with Acute lymphoblastic leukaemia and is given UKALL (trial) consolidation chemo, during this consolidation chemo the patient has several different combinations of chemo including Vincristine, Doxorubicine, Cytarabine and Cyclophosphamide.

1a. Are we correct in assuming this constitutes 1 treatment despite several combinations?

I agree.

1b. The patient then goes on to long term Oral maintenance chemotherapy with intrathecal chemotherapy with Cytarabine every 3 months, again there are many combinations of chemo given during this time. Are we correct in assuming this constitutes 1 subsequent treatment.

I agree

Scenario 2 - A patient was diagnosed with Mantle Cell Lymphoma, he is planned for a BEAM autograft followed by BEAM chemotherapy and autologous stem cell transplant, the transplant waiting list is under a great deal of pressure at present, and so they could give him a course of R/ESHAP as a holding manoeuvre should there be a significant delay.

2a. Are we right in assuming that any treatment to facilitate the stem cell transplant is all part of a single treatment or do we have to open subsequent treatment records for every episode of chemo leading up to the stem cell transplant?

You are correct (at least until there is definitive haematological specific guidance)

We have a Haematology 2ww which turned out to be Acute Myeloid Leukaemia. We treated the patient with chemo on day 41 - and Somerset is telling me that this is a breach. I thought it was only if the TWR was an Acute Leukaemia that we were open to the shortened Rare Cancer pathway. Am I wrong in thinking that then? And would the same apply to testes patients referred under the normal Urology TWR?

If a person is diagnosed with acute leukaemia they would be on the rare cancer 31d pathway even if the 2ww referral was for standard haematology. The same would apply to someone diagnosed with testicular cancer ie. they would be on the rare cancer 31d pathway even if they had come in as a standard urological cancer 2ww referral.

Could you please advise if we need to collect AI amyloidosis Myeloma patients? And if so, which ICD10 code should we use?

If this condition has a C code then yes it is included within cwts. If not then it is excluded. I would suggest that you check in the first instance with your clinical coders how this condition is usually coded. If this does not help let me know and I will seek advice from the NCIN/cancer registries.

Lower GI

A patient is referred in under the lower GI route. They are investigated and found to have a colorectal primary. Staging tests reveal a previously undiagnosed lung tumour, which is also a primary. The patient is still expected to have a treatment with the colorectal team, but is unable to at the present time due to the investigations required for the lung tumour. Would it be acceptable to put this time in between down as "active monitoring"?

I have discussed with DH and we agree that active monitoring is not appropriate in the scenario you describe. Under the old system you would have used a medical suspension because the patient is not fit for colorectal treatment due to investigations needed for lung cancer. There are no adjustments allowed for this now and the tolerance has been revised to take this into account. It is not appropriate to look to active monitoring just as a means to end the 31/62d period.

A patient with lower GI cancer, needs to have a short course radiotherapy prior to surgery. He has declined the date for surgery so the radiotherapy needs to be rescheduled when the patient is available again. Can we adjust that given he will be an outpatient and this will be done before the surgery.

No adjustment is possible for the r/t as this is an outpatient appt.

Skin

For a patient that is treated at their GP for skin cancer and is then referred in to the Trust for checking / possible further treatment, should the cancer status be 8? I assume the PCT should complete the first treatment on behalf of the GP on OE?

The treatment by the GP in primary care would be first treatment and the status would be Code 08. The PCT can upload on behalf of the GP but it is also possible for the Trust to do this if there is a local agreement for this. Any further treatment would be 31d subsequent.

Are the rules for skin cancer waits the same as those for other tumour types particularly in terms of DTT and the 31d standard?

I can confirm that the rules for cancer waits are no different for skin/suspected skin cancer than other tumour types.

The Decision to Treat (DTT) for the 31 day standard is the date that the patient and clinician agree a treatment plan. Using skin cancer as an example (with the advice being applicable to other cancer sites) the DTT to start the 31 day clock ticking could be the following:

- if the intent of an excision is purely diagnostic and is therefore just a biopsy (ie. a small sample to confirm a cancer diagnosis) and a treatment plan will still need to be discussed with the patient (including, for example, the full removal of the lesion that was initially just biopsied) then the DTT is the date the patient agrees to proceed with the further/full excision (or other treatment) after the biopsy - this would be the same as, for example, suspected bowel cancer eg. a biopsy may be taken at colonoscopy which confirms cancer and a DTT is then made after that to confirm the treatment plan;
- if the clinician suspects cancer (even if it was a routine referral) and is going to remove the full lesion (eg. a wider 'excision biopsy') which would in effect be the first treatment if it turns out to be cancer then the DTT is the date the patient agreed to this 'full' excision. Any further treatment that might then be needed would be a 31 day subsequent treatment - in this instance one would expect that the patient had been informed that cancer was a possibility and that this procedure would in effect be the first treatment if that turned out to be the case - this would be the same as, for example, suspected bowel cancer eg. a patient being told that cancer is suspected, a colonoscopy will be performed and a sample of anything suspicious found will be removed but that it may be possible to remove anything suspicious in its entirety at the time.

We are referred large numbers of patients with suspected skin cancers. The 'hit rate' from the GPs who refer by the Fast Track system is rather low, and only about 10% of those with 'suspected cancer' are eventually shown to have confirmed cancer. Inevitably, the diagnostic rate for the consultants is substantially higher, but there are still many patients in whom they cannot exclude cancer who are eventually shown not to have a skin malignancy. At present, ALL these patients in whom the dermatologists cannot confidently exclude malignancy are operated on within a 31 day pathway from the first outpatient consultation"

That is correct if the OPA was where the decision to treat (ie to remove the potential cancer) was made.

I am a core member of several site specific cancer MDTs, and I am aware that the rules in those MDTs are very different: the 31 day clock starts at the time of the decision to treat, not at the time of (for example) the rectal examination which shows a mass in the rectum, nor the time of the colonoscopy which shows a clinically obvious cancer which is biopsied. Why is it different for skin?

It is not. The DTT is the date the patient agrees to proceed with a particular treatment. It is true that a decision to have say a colonoscopy would not be the starting point for a 31d in most cases. However, if the clinician said that cancer was suspected, a colonoscopy would be done to have a better look and potentially take samples from anything found and that it might be possible to remove anything found totally then this would be a DTT ie patient agrees to have 'treatment' during a diagnostic procedure depending on what is found - ie the principle is the same as for suspected skin cancer.

Unless the rules are very different for dermatology, the decision to operate on the skin lesions is in fact a decision to biopsy; most often this will be a curative excision biopsy which will prove (or disprove) the diagnosis of cancer; this will result in a decision to treat, which will actually have been superseded by the biopsy itself. However, if the excision has been incomplete, there will need to be MDT discussion about further management, which will presumably result in a decision to treat with a 31 day timeline. Is that correct?

If it is genuinely a biopsy for diagnostic purposes then the DTT would be once the biopsy results were back and a treatment decision was then taken. If it is more than a biopsy ie you are removing all the lesion (or you think you are) and you know that if this is cancer then you will in effect have treated it then the DTT is the date it was decided to remove the lesion and potentially treat the suspected cancer. If the margins did not come back clear then the patient would be on a 31d subsequent treatment pathway for any further treatment.

I cannot see how there can be a decision to treat a cancer before there is even a diagnosis of cancer, and as such (so long as other deadlines are met, such as treatment within 62 days for a patient with cancer referred by fast track) we are seriously skewing our priorities and undertaking urgent excisions on people who do not have cancer, which is adversely affecting our ability to manage those with the most obvious and clinically most aggressive cancers in a timely fashion. What is your view on this?

In the example we are talking about, the issue is that there is a clinical diagnosis of cancer (not supported by pathology) or a probability of cancer and the diagnostic test would in effect treat it. If you have concerns about skewing of priorities you might want to write to DH setting out your concerns c/o timothy.hancox@dh.gsi.gov.uk .

In the patient who may have a skin cancer, is the first operative intervention a biopsy or a treatment, and when does the 'Decision to Treat' clock start?"

In essence it is a clinical decision based on what the patient has been told and what the procedure will have done if it turns out to be a cancer ie:

- if a small sample is being removed to confirm if it is cancer or not and if it is cancer the treatment plan will need to be discussed with the patient including full removal of the lesion then DTT is the Date the patient agreed to proceed with a further excision (or other treatment) after the biopsy - this applies to all cancers;
- if the clinician suspects cancer and is going to remove the full lesion and tells the patient that, if it turns out to be cancer, then this would in effect have treated it then the DTT to is the date the patient agreed to having the lesion removed - the same would apply for other cancers eg treating a potential bowel cancer at colonoscopy.

Patient referred in by GP under routine referral for a lesion or BCC. Patient is seen by consultant, added to waiting list as "urgent excision of lesions, BCC" and treated but not within 31 days. Referral is not upgraded to 62 day pathway at any stage as cancer not suspected. Histology proves sample to be a reportable cancer. How should this be reported?

This is an incidental finding of cancer and the Decision to Treat (DTT) date would be the same as the treatment date.

Patient referred in by GP under routine referral for a lesion, BCC or possible SCC. Patient is seen by consultant, added to waiting list as "urgent excision of lesion, BCC, possible SCC" and treated but not within 31 days. Again, referral is not upgraded to 62 day pathway at any stage as cancer not confirmed by consultant, but he thinks it could be possible SCC. Histology proves sample to be a reportable cancer

a) how should this be reported?

SCCs are within the remit of CWTs so this should have been a 2ww and if not preferably a consultant upgrade. If no upgrade was made the 31d standard for this scenario would start with the DTT via excision as this was treatment for a potential SCC.

b) Do you mean that DTT should be the date that the patient agreed to have the excision/treatment?

I have double-checked with DH and Yes the DTT is the Date the patient agreed to proceed with an excision because it was a possible SCC.

We receive a large number of Tertiary referrals. A|Consultant refers a Patient to us (Con to Con referral) as lesion, BCC or possible SCC but we do not have the original GP referral to support it and no pathway information is provided by the referring Trust so we do not know if the patient is on a 62 day pathway or a routine 18w referral. What should we do?

This is a matter that needs to be resolved locally - the mandated inter provider transfer dataset should help.

Upper GI

Could you please give some guidance on cancer patients waiting for a liver transplant (or other transplant) and how this affects the standards.

When the agreed treatment for a cancer is a transplant the DECISION TO TREAT would be when a donor has been found and the patient agrees to proceed with the procedure and the TREATMENT START DATE (CANCER) would be the admission date for surgery. There will not therefore be breaches of the 31-day standard as the DECISION TO TREAT DATE and the admission date will be within hours of each other. However, a breach could result for the 62-day standards as the patient may need to wait some time for an organ donor to become available following a two week wait referral, urgent screening referral or a consultant upgrade. The clock would therefore continue to tick while a donor was sought. These delays have been considered within the tolerances used to derive the operational standards, therefore, breaches are anticipated.

Should each episode of transarterial chemo embolisation (TACE) for subsequent treatment of liver cancer be recorded separately even though the same chemotherapeutic agent is being used? I should mention that after the first cycle, the patient has to have restaging scans to assess the efficacy of treatment etc and be seen again and then its decided if another cycle is needed, but the same drug is used. The decision to give X cycles of TACE is not made at the outset.

I don't know anything about TACE but each COURSE of chemo is counted as a subsequent treatment. Where there are changes in drug type or combo we need to be pragmatic ie if it was decided to change the drug mix but the treatment carried on uninterrupted I wouldn't class that as a subsequent treatment. The GFOCW advisory board advised that the key would be whether a new consent form had been signed or not ie. if it has then it should be classed as a new treatment and therefore a new 31d period. I hope that helps when considering your scenario but let me know if not and I will seek clinical advice.

Could you help in clarifying the rules for pancreatic stents?

The rules re pancreatic stents are not changed ie:

- Insertion of pancreatic stent CAN be classed as FDT if planned to resolve jaundice before the patient has a resection or starts chemotherapy. However, many clinicians agree that patients with mild obstructive jaundice (a serum bilirubin below 200 micromol/l) do not require biliary stenting before resection if surgery and imaging are planned within 7-10 days. If this is the agreed clinical practice locally then stenting for these patients will not count as the start of FDT
- Also, insertion of pancreatic stent is not an FDT if the original planned FDT is resection for pancreatic or related cancers (ampullary, duodenal and distal bile duct) but subsequently the patient requires a stent due to a delay to having the surgery.

Urology

Prostate

Some Trusts appear to have good performance on the urology pathway because they are putting large numbers of prostate patients on 'watch and wait' eg. if they are anything other than a straight forward surgical case they class them as 'watch and wait' whilst they undertake further staging investigations etc. Is this acceptable?

Active monitoring would be being used inappropriately if it is just a means to stop the clock earlier in the way you describe.

Active monitoring is where a diagnosis has been reached but it is NOT appropriate to give any active treatment at that point in time but an active treatment is still intended so the patient is monitored until a point in time when they are fit to receive or it is appropriate to give an active treatment. If a patient needs time to think about the treatment options they have been presented with then that is thinking time NOT active monitoring.

For example: active monitoring is a legitimate treatment option where the decision had been taken to monitor the progress of a specific condition for example a slow growing prostate tumour where there is not an immediate problem and it is clinically appropriate to step back and monitor the situation until an active intervention is more appropriate. It is not appropriate, if a patient has been presented with a number of treatment options eg open or lap prostatectomy or brachytherapy and they want to take some time to consider this or if the Trust does not have the capacity to deliver the treatment within the standard time.

DH has reviewed the operational tolerances and changed the 62d one from 95% to 85% to take into account that more patients will either choose to wait longer than 62d or will not be fit enough to be treated within that timeframe. The issue of the wait between TRUS biopsy and MRI was taken into account when setting the new tolerance.

In the longer term, DH could do an analysis on the use of active monitoring since the change over in how cancer waits are counted to try and identify and address inappropriate use.

A number of trusts are adopting a pathway incorporating MRI as a triage test - are there any national views on this approach?

Aware that this pathway is being carried out at some London centres. I understand that the idea is that it will provide better staging data. At present I believe that it is experimental but seems a reasonable thing to investigate. I don't see why there should be more breaches providing there is sufficient MRI capacity – in fact there may be fewer as there is no need to wait 4 weeks between MRI and biopsy. I have checked with the national clinical lead who agrees.

Is the Decision to Treat for brachytherapy the date of the volume study as that is when the decision is made that the treatment can proceed?

The DTT is '*the date that a patient agrees a treatment plan for first or subsequent treatments within a cancer care plan*'. In terms of brachytherapy I have advised that the date that the patient agreed to brachytherapy as their treatment would start the 31d clock and that the volume study is part of the prep for the brachy and takes place during that 31d period. You have previously noted that older cwt guidance states that the DTT is the date of the consultation where the treatment is agreed AFTER the volume study has been completed because the volume study is not part of the prep but part a procedure in order to determine whether the prostate is suitable for brachy. I have sought clinical advice from an expert in brachytherapy and he has advised as follows: '*My feeling would be that the volume study is the same as an anaesthetic assessment – which I think is NOT deemed to take place before the DTT but after. They only take place once the decision to use a treatment modality has been made but they are necessary prerequisites for the treatment.*' In view of this advice, I remain of the view that the DTT is when the patient agreed to proceed with brachytherapy which would be prior to the volume study.

Other urological cancers

A patient came in with a 3 month history of swollen testicle. Ultrasound of scrotum suggested possibility of right testicular cancer but the consultant did raise the possibility of lymphoma. After bloods and CT, the patient had a right orchidectomy the histology of which proved to be lymphoma (diagnosis is Stage IA right testicular diffuse large B cell lymphoma) Can we use the orchidectomy as the first treatment?

In my view, in this scenario the patient had a suspected cancer and both testicular and lymphoma were identified as possibilities. The decision after further tests was treatment by orchidectomy which confirmed that the patient in fact had lymphoma rather than testicular cancer. I would class the orchidectomy as the FDT and any further treatment of the lymphoma as subsequents.

Patient needs chemo for a urological cancer - chemo has to be delayed until patient has a stent to protect kidneys (ie. to stop tubes collapsing when chemo commences) - is insertion of the stent the FDT?

The general rule is that a stent can only be classed as first treatment where:

- the patient is unfit for any other treatment.
- the patient remained an in-patient between the date of admission for the stent and main surgery ie. if it is the same episode of care and surgery is the proposed treatment.

There are also a few specific examples where stents are allowed at FDTs:

- oesophageal stent
- NSCLC stent
- ureteric stenting for advanced cervical cancer
- insertion of pancreatic stent if planned to resolve jaundice before the patient has a resection or starts chemotherapy

In all other cases stents would have been classed as medical suspensions under the old cancer waits system and adjustments made. When DH calculated the new operational tolerances it took into account the level of medical suspensions previously uploaded onto the CWT-Db. The reduced tolerance therefore already allows for breaches due to enabling treatments needed prior to FDT that were not covered by the older guidance. The lower tolerance therefore takes into account patients that will breach because they need a stent apart from in the above scenarios.

In your scenario the stent would not be appear to be classed as FDT.

Miscellaneous

I keep hearing rumours of impending new targets - 2011 to 2015 ish, which relate to diagnosis within 7 days of referral, possibly breast, lung and colorectal. Obviously there is the earlier announcement in Sept of a major programme to ensure that all patients can undergo tests within one week of request by a GP – referred to as a 'PRIORITY FOR 2010' in the latest CRS Year 2 annual report – but is there anything specific on breast, lung, colorectal we can advise on?

I am not aware of anything on new targets other than:

- Cancer reform Strategy 2 year on report which summarises the position on improving access to diagnostics in primary care (para 3.27 & 3.28)
- NHS Constitution consultation which includes issues related to the 2ww for all announcement

Useful Links:

CWT Stats:

http://www.dh.gov.uk/en/publicationsandstatistics/publications/publicationsStatistics/DH_099885

CQC Indicators Constructions:

<http://www.healthcarecommission.org.uk/guidanceforhealthcarestaff/nhsstaff/annualhealthcheck/annualhealthcheck2008/09/qualityofs/nationalprioritiesacuteandspecialisttrusts.cfm>

GFOCW guidance:

<http://nww.connectingforhealth.nhs.uk/nhais/cancerwaiting/documentation#guidance>

Abbreviations/Acronyms

18w	18 week standard
2ww	Two week wait standard
31d	31 day standard
62d	62 day standard
AML	Acute Myeloid Leukaemia
Appt	Appointment
BCC	Basal Cell Carcinoma
CaB	Choose and Book
CA125	Cancer antigen 125 (a blood test)
CfH	Connecting for Health
CDS	Commissioning Dataset
CNS	Clinical Nurse Specialist
CWT	Cancer Waiting Times
CWTDb	Cancer Waiting Times Database
DH	Department of Health
DNA	Did Not Attend
DSCN	DataSet Change Notice
DTT	Decision to Treat
ECAD	Earliest Clinically Appropriate Date
FDT	First Definitive Treatment
GFOCW	Going Further on Cancer Waits
GP	General Practitioner
HCP	Health Care Provider
ISB	Information Standards Board
LGI	Lower Gastro Intestinal
LHB	Local Health Boards
METS	Metastatic Disease
MHRA	Medicines & Healthcare Products Regulatory Agency
MRI	Magnetic Resonance Imaging
ODS	Organisation Data Service
OE	Open Exeter (ie where the CWTDDB is located)
OPA	Outpatient Appointment
PCT	Primary Care Trust
PDS	Personal Demographics Service
PET	Positron Emission Tomography
PPI	Patient Pathway Identifier
pTa	a low grade bladder tumour
Pt	Patient
PTL	Priority Target List
r/t	Radiotherapy
RTT	Referral to Treatment Time
SCC	Squamous Cell Carcinoma
SSP	Specialist Screening Practitioner
TCI	To Come In Date
TIPSS	Transjugular Intrahepatic Portosystemic Stent Shunt
TOP	Termination of Pregnancy
TURBT	Transurethral Resection of Bladder Tumour
TURP	Transurethral Resection of the Prostate
TWR	Two Week Wait
Tx	Treatment
UBRN	Unique Booking Reference Number