

UKACR Quality and Performance Indicators 2008

TECHNICAL NOTES FOR COMPLETING PRO FORMA

GENERAL NOTES

1. Years

Data should be provided for 2006 for tables 1 to 3 (except Scotland who are submitting 2005 data for tables 1, 2 and 3).

2. Tumours

Registrations should include all malignant tumours, excluding non-melanoma skin cancer (All xnmisc).

ICD 10: C00 - C97 Excluding C44

Breast and cervix in situ (ICD10: D05, D06) have been added separately to Table 2 only, but should not be counted in the "All sites" total.

3. Population

The population covered should be the **residents** of the registry's catchment area only as defined by the Cancer Postcode Directory. (The list of Lower Super Output Areas (LSOAs) can be found on the UKACR website www.ukacr.org in the member's section under projects/shared resources/postcodes/Cancer Postcode Directory January 2008 (zipped text) using the January 2008 file. The population figures should be taken from projects/shared resources/Populations/Version 5.0/LSOA population denominators 1981-2005 for the year 2005).

TABLE 1

- 4.** The ratio of registered (malignant tumours all xnmisc) to expected cases for the year 2006 should be measured at 30/06/2008, where the expected number of cases is estimated using the average number of registrations for the years 2003-2005.

The number of registrations in each year 1997-2005 should also be provided.

Some registries may wish to distinguish between "Initial registrations" and registrations that are "ONS ready". The term "ONS ready" means that the registrations are of a standard usable for analysis and in publications. They are of a standard to send to ONS - although they do not actually have to have been sent to ONS. This does not preclude

registrations with missing fields and ones where more data may be received (e.g. on treatment) at a later date.

TABLE 2

The following ICD10 codes should be used: “Lung” (trachea, bronchus & lung: C33-C34), invasive breast (C50 - females only), in situ breast (D05 - females only), invasive cervix (C53), in situ cervix (D06), melanoma of the skin (C43), colorectal (C18-C20), prostate (C61), bladder (C67), haematology (C81–C96), ill-defined sites (C76-C80), all sites (C00-C97, excluding C44).

5. “DCO” rates

These should exclude GP only (GPO) and Post Mortem only (PMO) cases. If this is not possible then please specify what is included in the calculation. (or see Library of Recommendations, Po/03/03.)

They should be based on 2006 (except Scotland).

The denominator should include all malignant tumours xnmisc for the particular cancer site(s) of interest.

For the all sites calculations, these should be broken down by sex and age at diagnosis (<75, >=75 yrs) also.

6. "True" DCO rates

Note: this measure is based on the Quarterly PIs. However, this should be based only on registrations within the catchment area of your registry and only on all malignant tumours xnmisc.

The denominator should include all malignant tumours xnmisc for the particular cancer site(s) of interest.

They should be based on 2006 (except Scotland).

The numbers of cases that were death certificate initiated and for which no ‘corroborating evidence’ has yet been found as at 30.6.2008, and for which follow-up is complete. (See Library of Recommendations, Po/03/03.)

By definition, there should not be any GPO or PMO cases which are flagged as being “True” DCOs.

For the all sites calculations, these should be broken down by sex and age at diagnosis (<75, >=75 yrs) also.

7. Zero survival rates

They should be based on 2006(except Scotland).

The denominator should include all malignant tumours xnmisc for the particular cancer site(s) of interest.

This should include any cases where the date of diagnosis = date of death (including the “True” DCOs, and any “DCOs” that are still being followed up).

For the all sites calculations, these should be broken down by sex and age at diagnosis (<75, >=75 yrs) also.

8. Microscopic verification

Registrations should be considered microscopically verified where diagnosis is based on a malignant histology report for either the primary or of metastases of the primary tumour, cytology report, bone marrow report or blood report. (N.B. The registry may not have seen, or possess the report).

The denominator should include all malignant tumours xnmisc for the particular cancer site(s) of interest.

9. Stability of incidence

This measure is defined here as the % increase in the number of registrations this year compared with the average of the previous 3 years, as currently on the database as at 30/06/2008.

$$\left\{ \left(\frac{\text{Number of registrations in current year}}{\text{Number of registrations in previous 3 years}/3} \right) - 1 \right\} * 100$$

10. Childhood incidence rates

Age-specific incidence rates in the age groups specified should be used.

All malignant tumours xnmisc should be included.

The rates should be calculated using mid year 2005 LSOA derived populations as the denominator (also 2005 for Scotland).

11. Mortality to incidence ratios

M:I = deaths in specified period, with diagnosis C as underlying
incident cases in period with diagnosis C

For England and Wales, mortality data supplied for CIS by Thames for the registered deaths should be used for the numerator, not deaths as recorded by the registry.

Equivalent data of the numbers of deaths should be provided by Northern Ireland and Scotland. Mortality data for 2005 should be used by all registries to remain consistent.

12. Specificity of morphology: the proportion with a non-specific morphology code for those cases which have been microscopically verified

The denominator should include all tumours which have been microscopically verified (point 8) for the relevant cancer site(s) of interest.

The number of cases whose morphology is M8000, M8001 or M8010 should form the numerator for this measure for the relevant cancer site of interest, except for haematology.

For haematology, the non-specific morphologies counted in the numerator should be either M9800 or M9590.

For the “All xnmsc” total, the denominator should include only all xnmsc cases (i.e. not including the in situ cases) that have been microscopically verified (i.e. not including the in situ cases). The non-specific morphologies counted in the numerator should be M8000, M8001, M8010, M9800 and M9590.

(OPTIONAL EXTRA: please note that several registries have requested that the additional internal check for looking at the proportion of cases with a specific morphology code which have not been microscopically verified, also be included in the template to allow for internal QA checks. This has therefore been left in table 2 in the template, and if you wish to complete the fields, please do so using the following definitions:

The denominator should include all tumours which have **NOT** been microscopically verified (point 8) for the relevant cancer site(s) of interest.

The number of cases whose morphology is **NOT** one of M8000, M8001 or M8010 should form the numerator for this measure for the relevant cancer site of interest, except for haematology.

For haematology, the specific morphologies counted in the numerator should be those whose code is not one of M9800 or M9590.

For the 'All xnmisc' total, the denominator should include only all xnmisc cases (i.e. not including the in situ cases) that have not been microscopically verified. The specific morphologies counted in the numerator should be those cases whose codes are not one of M8000, M8001, M8010, M9800 and M9590.

TABLES 3A – 3F

13. Database check - Table 3a - demographics and diagnostic details:

All database records for all malignant tumours xnmisc should be checked for completeness and validity:

% Blank The record contains no entry for that data item.

% Invalid The record contains a code for that data item, but it is not a valid code.

% Valid Unknown The record contains a valid code for that data item, but the code means that data item unknown.

% Valid Known The record contains a valid code for that data item, and the data item takes a known value.

For each row of the database the four columns should sum to 100%.

Notes:

Name, Address, Postcode: There should be no *Valid Unknown* cases for these data items – please identify what they are if you have some.

Sex: All options are possible.

Date of birth, Unique Health Identifier (NHS Number for England and Wales; Community Health Index (CHI) for Scotland and Unique Health and Social Care number for Northern Ireland): There should be no *Valid Unknown* cases for these data items – please identify what they are if you have some.

Ethnicity: For English registries, only the standard code set as defined by the relevant DSCN issued in 2000 (212000.pdf) and supplemented in 2001 (022001.pdf), both found at <http://www.connectingforhealth.nhs.uk/dscn/dscn2001/022001.zip> in line with the NCDS should be counted as a *Valid Known* code; except for code 'Z' or '99' = not stated which should be counted as *Valid Unknown*. Thus, only cases with either one of the 16 other single letter code, or one of the 89 other double letter codes should be counted as being a *Valid Known* code. Similar definitions for the non-English

registries should be used based on the 2001 Census in each of these countries.

Any other ethnicity systems being used which do not conform to these codes, should be described as being *Invalid*.

Anniversary (diagnosis) date: There should be no *Valid Unknown* cases for this data item – please identify what they are if you have some.

Site of primary: *Valid Unknown* is defined as C76-C80.

Date of death: These should be calculated using the total number recorded as dead as the denominator. There should be no *Valid Unknown* cases for this data item – please identify what they are if you have some.

Type of growth: *Valid Unknown* is defined as M8000, M8001, M8010 with no microscopic verification (see point 8), M9800 or M9590. (i.e. the ‘with no microscopic verification’ applies only to M8010).

Behaviour of growth: There should be no *Valid Unknown* cases for this data item – please identify what they are if you have some.

Basis of diagnosis: All options are possible.

14. Database check - Table 3b - treatment:

All database records for all malignant tumours xnmisc should be checked for completeness and validity, UNLESS a different denominator is stated for the particular data field:

% Blank The record contains no entry for that data item.

% Invalid The record contains a code for that data item, but it is not a valid code.

% Valid Other The record contains a valid code for that data item, but the code means that data item is either NO or Unknown.

% Valid “Yes” The record contains a valid code for that data item, and the data item takes a known value of YES.

For each row of the database the four columns should sum to 100%.

Notes:

TREATMENT INFORMATION:

For all four treatment variables, the treatment information should be as defined by ONS and relate to the first 6 months from diagnosis only (include short negative diagnosis to treatment days). If it is known that the patient did **not** have any treatment then this should be included in *Valid Other* rather than *Valid “Yes”*.

% Unknown Treatment: *Valid “Yes”* should include the % for whom no indication of treatment can be found and should exclude Death Certificate Only registrations from the numerator and denominator. The % Blank, % Invalid and % Valid Other categories are not meaningful in this instance. Percentages should be calculated for all malignant tumours xnmisc, female breast, cervix, melanoma and colorectal tumours.

% Surgery: *Valid Known* should be the % who received surgery known to be **THERAPEUTIC** as a proportion of all xnmisc registrations. These cases are said to be ‘**surgically treated cases**’. If it is known that the patient did **not** have any surgery OR had surgery which was only **DIAGNOSTIC** in nature, then these cases should be included in *Valid Other* rather than *Valid “Yes”*.

% Radiotherapy: *Valid Known* should be the % who received radiotherapy of any intent as a proportion of all xnmisc registrations. If it is known that the patient did **not** have any radiotherapy, then this should be included in *Valid Other* rather than *Valid “Yes”*.

% Chemotherapy: *Valid Known* should be the % who received chemotherapy of any intent as a proportion of all xnmisc registrations. If it is known that the patient did **not** have any chemotherapy, then this should be included in *Valid Other* rather than *Valid “Yes”*.

% Hormone treatment: The denominator for these cases should be **either only female breast cancers or only prostate cancers**, rather than all xnmisc registrations (and these should be reported separately). *Valid “Yes”* should be the % who received hormone therapy of any intent as a proportion of either all female breast cancer or prostate registrations, respectively. If it is known that the patient did **not** have any hormone therapy, then this should be included in *Valid Other* rather than *Valid “Yes”*

15. Database check - Table 3c - screening information:

Only data provided directly by the QARCs should be reported on and for 2005 cases **NOT** 2006 (also 2005 data for Scotland).

Screening status for invasive female breast tumours:

For the age-group, 50 to 67 inclusive at diagnosis (upper age limit + 3 years to allow for possible diagnosis of interval cancer – we have

chosen to stick with 67 as the upper limit because not all screening programmes will have rolled out the age extension yet), the two following measures of breast cancer are required:

% Screen-detected of the valid age group: Only breast cancer cases flagged as being screen detected should be counted as *Valid "Yes"*.

% of cancers with a full screening category within the valid age group: The list below identifies the *Valid "Yes"* and *Valid Other* categories (derived from the NCDS). Null values are counted as *Blank* and any other values are *Invalid*.

Screen Detected - valid "Yes"
Interval Cancer - valid "Yes"
Other (eg lapsed attended) - valid "Yes"
Not known - valid "Other"
Uncategorised - Invalid

Screening status for invasive cervical tumours:

For the screening age-group, 25 to 67 inclusive at diagnosis (upper age limit + 3 years to allow for possible diagnosis of interval cancer), the following measure should be reported:

% Screen-detected of the valid age group: Only cervical cancer cases flagged as being screen detected should be counted as *Valid "Yes"*.

16. Database check - Table 3d - specific staging information including grade:

Following work undertaken by the UKACR QA Group, the UKACR Registration Subgroup, the final decisions about which specific staging system should be reported for the four cancer sites of interest (female breast cancer, colorectal cancer, cervical cancer and melanoma of the skin) were agreed by NCRAG on 16/05/2007. All database records for the particular cancer sites of interest should be checked for completeness and validity against these specified staging systems for the particular cancer sites of interest:

- % Blank The record contains no entry for that data item.

- % Invalid The record contains a code for that data item, but it is not a valid code.

- % Valid Unknown The record contains a valid code for that data item, but the code means that data item unknown. Where a tumour is unstageable this should count as *Valid Unknown* and not staged.

- % Other Known The record contain a valid code for that data item which belongs to a different staging system to that specified for

the particular cancer site of interest. Use this if you are not sure which staging system is being used; ie you do not know that the specific staging system for the cancer site is definitely being reported.

% Valid Known The record contains a valid code for that data item, and the data item takes a known value for the specified staging system for the specified cancer site of interest. You must only use report this (rather than 'Other Known') if you definitely know that the stage has been reported using this staging system.

For each row of the database the five columns should sum to 100% (as you will either have included the case as having a valid known (if using specified staging system) or Other Known (if you are not sure whether the staging system is the specified one; or you know that it is definitely not the specified staging system).

Notes:

The following specific measures should be reported for female breast cancer, colorectal cancer, cervical cancer and melanoma of the skin:

Female Breast cancer - % with known Bloom and Richardson grade: All invasive female breast cancer cases should be examined. Of these only those with known Bloom and Richardson grade (i.e. G1-G3) should be counted as *Valid Known*.; G4 should be included as being as *Invalid Known* (so put in the invalid column); GX should be included as being *Valid Unknown*.

For any cases where it is not known whether or not the grade is according to the modified Bloom & Richardson histological grading system should be reported as being *Other Known* rather than *Valid Known*.

Registries are asked to update the information relating to how many of their NHS pathology laboratories are using this classification, finding out this information if it is unknown, where possible; plus including details of any laboratories who are not yet submitting pathology data to the registry (collated in table 3f in the template)

Female Breast cancer - % with known number of positive nodes: All invasive female breast cancer cases should be examined. Of these only those cases who are known to have had nodes removed and for whom it is known how many of these were positive (ie a known number of positive nodes) should be counted as *Valid Known*. Those cases where the number of positive nodes is zero should be included as *Valid Known* as long as the women definitely had nodes removed. Cases which are known to be node positive, but the exact number of nodes is

unknown should be counted *Valid Unknown*. These should only be regional axillary nodes, and not the intramammary nodes.

Cases where only a Sentinel Lymph Node Biopsy (SLNB) was performed can be included only if the SLNB was negative. This then can be taken as zero positive nodes and so have a *Valid Known* code for these cases. For cases where the SLN was positive, then this information cannot be used (as unknown exactly how many nodes would be positive) and the case should be counted as *Valid Unknown*.

Any cases using TNM or other staging systems, or where the staging system is unknown, should be recorded as *Other Known* rather than *Valid Known*.

Female Breast cancer - % with known invasive size: All invasive female breast cancer cases should be examined. Of these only those with the known exact invasive size should be counted as *Valid Known*.

Any cases using TNM or other staging systems, or where the staging system is unknown, should be recorded as *Other Known* rather than *Valid Known*.

Female Breast cancer - % with known NPI score: All invasive female breast cancer cases should be examined. Of these only those with a known NPI score should be counted as *Valid Known*. However, if the three separate components are known then these cases can be included as having a valid known NPI score because it is acceptable to apply the calculation used to derive the NPI score from the three separate components. This calculation is:

$$\text{NPI score} = \text{Histological Grade} + \text{Nodes} + 0.2 \times \text{Invasive Size of Tumour (in cm)}$$

where

Grade takes values 1, 2 or 3 (using Bloom and Richardson grade as defined above)

and

Nodes = 1 if zero nodes are positive
= 2 if 1–3 nodes are positive
= 3 if ≥ 4 nodes are positive

These should only be regional axillary nodes, and not the intramammary nodes.

Cases where only a Sentinel Lymph Node Biopsy (SLNB) was performed can be included in the calculation only if the SLNB was negative. This then can be taken as zero positive nodes and so have a

Valid Known code for these cases. For cases where the SLN was positive, then this information cannot be used (as unknown exactly how many nodes would be positive) and the case should be counted as *Valid Unknown*.

Any cases using TNM or other staging systems, or where the staging system is unknown, should be recorded as *Other Known* rather than *Valid Known*.

Colorectal cancer - % with known pathological Dukes stage: - All invasive colorectal cancer cases should be examined. Cases with a known pathological Dukes stage, or one derivable from a TNM stage according to the conversion table in Appendix 1, should be counted as *Valid Known*; except cases known to have metastases at diagnosis can be taken as being Dukes Stage D and hence have a *Valid Known* code.

Cases who are known to have died within a short time of the colorectal cancer should not be counted as being Dukes Stage D, and unless Dukes pathological staging is known at diagnosis, this should be reported as *Valid Unknown*.

Any cases using other staging systems, or where the staging system is unknown, should be recorded as *Other Known* rather than *Valid Known*.

Cervical cancer - % with known Complete FIGO stage: - All invasive cervical cancer cases should be examined. Of these only those with a known Complete FIGO stage, or known pT stage, should be counted as *Valid Known*.

Any cases using other staging systems, or where the staging system is unknown, should be recorded as *Other Known* rather than *Valid Known*.

Melanoma skin cancer - % with known Breslow thickness: - All invasive melanoma skin cancer cases should be examined. Of these only those with a known Breslow thickness should be counted as *Valid Known*.

Any cases using TNM or other staging systems, or where the staging system is unknown, should be recorded as *Other Known* rather than *Valid Known*.

Melanoma skin cancer known Clarke level: - All invasive melanoma skin cancer cases should be examined. Of these only those with a known Clarke level should be counted as *Valid Known*.

Any cases using TNM or other staging systems, or where the staging system is unknown, should be recorded as *Other Known* rather than *Valid Known*.

All registries are asked to include a statement for each site explaining whether how they report stage is different from as was reported in 2007 (collated in table 3f).

17. Interaction between the QARCs and the Cancer Registries - Table 3e:

The QARCs and Registries are beginning to establish regular exchanges of data. Descriptions of how well this is progressing for both breast and cervical cancer is examined in this table.

TABLE 4

18. Final Specification for Flow method of completeness of ascertainment

Two separate files of diagnoses and a file of deaths on which to run the Stata Flow Method program *complims.ado* should be obtained on 30/06/2008:

- (i) Extract all diagnoses on the database in 2004 for all xnmisc cases to obtain 2-yr completeness
- (ii) Extract all diagnoses on the database in 2001 for all xnmisc cases to obtain 5-yr completeness
- (iii) Extract all deaths on the database in 2006 for all deaths.

These files should be cleaned to exclude:

1. DCOs or DCIs without a date of death;
2. DCOs with date of diagnosis not the same as date of death;
3. Non-DCOs who have date of diagnosis the same as date of death;
4. Cases not belonging to the Registry's region;
5. Non-melanoma skin cancers;
6. Non-malignant tumours;
7. DCOs and DCIs with date of registration preceding date of death;
8. Cases with date of diagnosis later than date of death;
9. Cases aged less than 0 or greater than 120 at diagnosis;

10. Cases with missing values for sex, date of birth, date of diagnosis or date of registration.

(Note: Whether or not all of the above are relevant will probably be registry-specific. For example, point 2 could not happen in registries who use “date of death = date of diagnosis” as part of the definition of a DCO.)

These files should contain the following variables (using the specified names):

1. dco	Death Certificate Only flag	(0 = No; 1 = Yes)
2. dci	Death Certificate Initiated flag	(0 = No; 1 = Yes)
3. diagd	Date of diagnosis	
4. deathd	Date of death	
5. icd10_si	Code for site of tumour	(Does not need to be ICD10.)
6. newid	ID number	
7. birthd	Date of birth	
8. regd	Date of registration	
9. sex	Sex	
10. died_of	Death cause (0 = Cancer not mentioned in Death Certificate; 1 = Cancer mentioned in Death Certificate)	

Note: Date of birth and date of diagnosis will be used by David Robinson to calculate the age at diagnosis to run on the whole England and UK files to allow comparison with the CCRG running the analyses on their database.

All dates should be in Stata ‘elapsed date’ format (see **Stata User’s Guide**).

Newid is a unique identifier. This should be set equal to the 11 digit ONS tumour number. The reason for using this is to help to identify the true year of registration if this is unknown (see below).

For this analysis, a DCO case is one for which the registration is made solely on the basis of the death certificate. A DCI case is one for which the initial registration was made from the death certificate. This will include both DCOs (which are DCIs by definition) and those cases for which additional information was subsequently successfully traced in order to obtain a date of diagnosis. It is important that a case originally registered as a DCO which is subsequently traced should then be “un-DCOed” – i.e. the DCO flag should be reset to 0 whilst the DCI flag is left as 1. If the user wishes to run the program with the DCO ‘fix’, then both DCO and DCI must be present on the files. However, if the ‘fix’ is not required (i.e. when running the program with the **xdco** option) then neither variable is necessary.

Date of registration is the date on which information on the tumour is first entered onto the Registry’s computer system.

Also note:

- All tumours should be included in the diagnoses files
- If the year of ‘true’ registration is known, then assigning a registration date in the middle of that year is probably sufficient. The ONS number can be used to determine the year of registration and “30/06” used as the “dd/mm” part of the date. If this is not possible and the year of registration is not known, then the date of registration should be set to missing and the cases excluded from the calculations. Some Stata commands to help produce this is reproduced following Table 1 in the UKACR Statistics and Information Manual Chapter “Use of the Flow Method for estimation of completeness of cancer registration”

In the *complims.ado*:

- (i) use the *xdco* command in the syntax
- (ii) use 31/12/2006 as the truncation date in the syntax

Run the analysis on the 2004 diagnoses, 2006 deaths files to obtain 2-yr completeness estimates for the sites: (a) all xnmisc, (b) lung cancer, (c) breast cancer, (d) colorectal cancer, (e) prostate cancer, (f) bladder cancer, (g) haematological cancers, broken down by both sexes for (a), (b), (d), (f) and (g).

Repeat the analysis on the 2001 diagnoses, 2006 deaths files to obtain 5-yr completeness estimates for the sites: (a) all xnmisc, (b) lung cancer, (c) breast cancer, (d) colorectal cancer, (e) prostate cancer, (f) bladder cancer, (g) haematological cancers, broken down by both sexes for (a), (b), (d), (f) and (g).

The site code definitions are as per the Table 2 above.

The final Stata files used by each registry to run the completeness algorithm are required to be sent to David Lemon at NWCIS (david.lemon@nhs.net) to calculate England and UK figures.

COMMENTARY

This report will need to cover the reasons for any measures not met, either against peer review targets, or against target/expected values for non-peer review measures as detailed in the separate *measurestemplate2008.xls* file.

Collated results will be sent to each registry using the new UKACR measures template to determine whether a comment should be made regarding their figures for a specific measure. If any measure for a particular registry is below the Peer Review, expected or target value, or is “not in line” with other registries then the registry should assess whether this is a genuine shortfall. All genuine shortfalls must be commented upon.

You should also include the information you supplied in tables 3e and 3f in the commentary.

Details of progress made since last year, in particular with registration processes and data quality can also be included in the report.

APPENDIX 1: CONVERSION OF TNM TO DUKES STAGING

TNM profile can be converted to Dukes Staging by using the table below. The “T”, “N” and “M” components refer to any pathological (e.g. pT1pN0pM0) or clinical (e.g. cT2cN0cM0) certainty factors.

TNM stage Profile	Summary Stage	Dukes Stage
T1N0M0 T2N0M0	I	A
T3N0M0 T4N0M0	II	B
Any T N1M0 Any T N2M0	III	C *
Any T Any N M1	IV	D

* Dukes C can be further divided into two categories - C1 where the apical node is NOT involved and C2 where the apical node is involved. However this is not normally part of the TNM staging and cannot be derived from the TNM profile.

“X” in the TNM profile

In the Case of “MX”, it can be assumed in the absence of any other data that the clinician has decided that the patient has no distant metastases i.e. “cM0”

TNM stage Profile	Summary Stage	Dukes Stage
T1N0MX T2N0MX	I	A
T3N0MX T4N0MX	II	B
Any T N1MX Any T N2MX	III	C
TXN0M0	II	B
TXN1M0 TXN2M0	III	C