UKIACR ANNUAL PERFORMANCE INDICATORS 2014

COMMENTARIES

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COMMENTARY FOR ENGLAND

General

The National Cancer Registration Service (NCRS) is proud to submit a single set of performance indicators for the whole of England for the first time.

The 2012 data, extracted from the English National Cancer Online Registration Environment (ENCORE), are testament to the service's collective ability to continue to provide high quality cancer registration data despite the many challenges faced during the last 12 months, including transfer into Public Health England (PHE) and migration onto ENCORE. These conflicting pressures have meant that the service has needed to prioritise in order to maximise the overall value and quality of its 2012 data.

There are clear success stories in the 2012 data. The NCRS has maintained its incidence rates and microscopic verification rates. The most significant change from last year has been the dramatic improvement in staging rates for invasive cancers: moving from 51% for last year to 62%. Within this, the NCRS has recorded stage rates of above 80% for the priority cancer sites of breast, colorectal, lung, ovarian and prostate. It has done so by acting as a cohesive national service working on a single system.

There are some areas for improvement - because of the challenges due to migration, maintaining past performance against some measures, particularly DCO rates, has been extremely difficult. The service is pleased that the Performance Indicators have raised awareness of these areas, and plan to address them over the coming months.

Overall, these data provide a good first submission for the NCRS of England. These data provide a solid foundation for the service to build on over the coming years and were only achievable because of the commitment, expertise and teamwork of our staff.

Changes in Registrations

All cancers (C00 – C97 ex C44):

The overall rise of 1.1% is typical compared to previous years, and is average for the UKIACR. The rise in the number of cancers is primarily driven by an aging population.

Melanoma Skin:

Incidence of Melanoma Skin has been rising nationally for several years now. It is believed that this is likely to be a true increase.

Male Colorectal:

The increase is average for the UKIACR, and part of an established trend following the roll-out of the bowel screening programme.

Female Lung:

The increase is average for the UKIACR, and part of an established trend of increasing rates of female lung cancer

Breast cancer:

The increase in invasive breast cancer is average for the UKIACR, and part of an established trend of increasing rates of breast cancer

A change in registration practice was made in 2012, where it was agreed that if an in-situ pathology report was received prior to an invasive one and there was no clear evidence that invasion was suspected initially then two registrations should be made, of both the in-situ breast cancer and the invasive breast cancer. Previously, it is possible that only an invasive tumour would have been registered. This may have created an artificial rise in the number of in-situ breast cancers. There could also be an impact of the phased extension of the screening programme.

Cervix in situ:

There do appear to be noticeable shortfalls in the number of cervical cancers in certain geographical areas of England. However, all routine sources of data in these areas have been loaded and processed. The fall in the number of cases is compared to a three year average that still includes 2009, in which the high profile death of the celebrity Jade Goody from cervical cancer occurred. It is felt that some of the fall is a reduction back to pre-Jade-Goody levels of detection. The short fall in the incidence of in situ cervix in some of the regional offices may be linked to the

fact that they have not been regularly exchanging data with the cervical QARCs. We are now reviewing our data exchange with the QARCs and hope to improve this in 2014.

Haematological Cancers

The fall in the number of haematological cancers is primarily driven by inconsistencies in the classification of some haematological cancers in previous years artificially inflating the number of haematological cancers in the baseline.

This affects morphologies 9960, 9961, 9962, 9980, 9981, 9982, 9983, 9984 and 9989 – approximately covering myeloproliferative disorder, thrombocythemia, and myelodysplastic syndrome. Originally in ICD 10 and ICD O2 these tumours were borderline (behaviour 1), and so should not have been submitted to the PIs as malignant/invasive tumours. However, in ICD O3 these tumours were reclassified as malignant tumours (behaviour 3). The 2012 data has correctly coded these cancers as invasive in ICD O3, but borderline in ICD10 / ICDO2 (and so excluded them from the PI totals), but as previously registries were (incorrectly) coding these as invasive in ICD10 this change has resulted in a fall in the overall numbers. These tumours should not be on ENCORE as malignant in ICD 10, and so should be excluded from the PIs. For 2012, which was finalised on ENCORE, the data are correct, but for previous years the miscoded tumours are still on the system. (This is very similar to the problem with the borderline ovarian tumours, which was rectified this year). We now plan to do a bulk resolve of these tumours, as we did for the ovarian cancers.

Death Certificate Only rates (and zero day survivors)

The DCO rates have risen for all cancer sites in England in 2012 compared to 2011. It was an accepted risk within NCRS that the effort required to achieve migration and the focus on the five sites for staging would mean that there was less time to complete full follow-up of death certificate only cases and thus there would be an increase in DCO rates. However, we are reviewing this going forwards, and hope to see a fall in DCO rates for 2013.

Completeness of the dataset - patient demographics

Address:

Investigation shows that these patients do have an address recorded against them, but it is not possible to identify the address at diagnosis. These are a very small number of patients, and will be reviewed to attempt to identify whether the recorded address is the address at diagnosis.

Completeness of dataset – treatment information

Radiotherapy:

Historically, regional registries had processed data from NatCanSat. However, due to migration, these feeds were interrupted, and so some regions (particularly London) were unable to complete their usual process. We are reviewing how to resolve these issues, either by establishing a single feed of data from NatCanSat, or obtaining data locally from Trusts. Early 2013 treatments may be missed but should get added during the course of 2014.

Chemotherapy:

The proportion of cases with chemotherapy has fallen slightly, but is broadly comparable to last year's figures. The slight fall may be due to the fact that early 2013 data was not processed for all branch offices before 2012 cases were finalised, leading to an expected slight deficit in treatment for patients diagnosed late in 2013. These cases will be processed as the 2013 cases are loaded and processed. The creation of the Systematic Anti Cancer Therapy dataset, which now exchanges Fact Of Chemotherapy data directly with the NCRS, should also enable us to improve in 2013.

Prostate cancer treatment rates:

The high proportion of prostate cancers with reported treatment is a success of the NCRS. The increase in recorded treatment for the older age groups reflects both clinical practice and the fact the prostate was one of the sites that was focussed on for staging so there was a focussed work programme to follow-up these cases.

Completeness of dataset – screening information

Screening data (breast and cervix):

The preparations for receiving the Cancer Outcomes and Services Dataset (COSD) from all Trusts in England, coupled with the challenges of migration, have made the previous year a very difficult one for data liaison teams. Similarly, the move to PHE has meant disruption in the QARCs. Because of this, screening data flows have been interrupted from several QARCs, and when data was received a new way of processing it into a new system was needed. The NCRS now has a screening data co-ordinator role, who is reviewing the submissions from all Trusts and prioritising

the loading of this data onto the system. This should enable us to back populate missed 2011 data and improve for 2012.

Completeness of dataset – site specific information for breast cancer

NPI score:

The proportion of tumours with an NPI score has fallen this year. This is because of the migration. Historically, local registries would derive the NPI score from constituent parts, either by calculating it by hand or by algorithms in their software. For this first year as a National Cancer Registry, only cases when a calculated NPI score was submitted from the Trust were recorded in the system – no NPI scores were calculated locally. This is because resources were focussed on priority development related to migration. We do not expect a fall in the number of tumours on ENCORE which have grade, tumour size, and nodal status, and so NPI score can be derived for these patients. We will work to automatically calculate NPI score for these tumours, and make this available in the CAS.

COMMENTARY FOR NORTHERN IRELAND

General

Northern Ireland has a regional database for the electronic capture of information gathered at multidisciplinary team meetings, known as CaPPs (Cancer Patient Pathway System). This has enabled capture of data in a timelier manner, as we are now able to identify people earlier that would have eventually come to the registry as DCI cases. This may explain the higher than expected number of registrations for 2012. Also, there has been a slow but steady increase in cancer incidence, as seen in Table 1, reflecting our aging population.

Change in registrations

Male melanoma:

Each of these cases has been histologically verified and staging information assigned. We believe that the increase of 24.1% is a genuine increase, similar to that reported by England.

Male colorectal:

The increase of 11.1% reflects increased numbers of screen detected cases in the prevalence round. Screening began in the one Health Trust in 2010 and since then has been rolled out to the other health trusts.

Female lung:

The increase of 13.5% may in part be due to more timely identification of cases via CaPPs, enabling identification of people who would have eventually come to NICR as a DCI case, often elderly ladies. This also reflects the increasing numbers of women smoking.

Cervix in situ:

We have re-checked and believe that the fall of 29.5% is genuine and a return to normal after the rise following the media coverage of the diagnosis and death of Jade Goody. In our next exchange of data with QARC, we will also include CINIII's which will help verify the information.

Haematology:

The fall in both males (8.5%) and females (18.4%), is due to the implementation of ENCR rules on standard registration for haematological malignancies. A detailed review of haematological registrations was undertaken to identify/ remove tumours that should now be considered as single registrations by ENCR rules.

Mortality: Incidence ratio

Cervix invasive:

The M:I ratio for cervical cancer during this period was 0.24. The cervical cancer rate often fluctuates in our data due to small numbers. The incidence of cervical cancers fluctuated from 89 to 129 (2008- 2012), with deaths ranging from 19 to 28 (2008-2012).

Melanoma of skin:

The M:I ratio for melanoma skin cancer during this period was 0.12. Again, there are fluctuations in our data due to small numbers, for example, the number of deaths between 2008 and 2012 ranged from 42 to 66.

Colorectal:

The M:I ratio for colorectal cancer during this period was 0.33. There has been a decreasing trend in colorectal mortality in NI, and the recent introduction of screening may in part explain the increase in incidence.

Bladder:

The M:I ratio for bladder cancer during this period was 0.60. There is strict application of the rules regarding bladder cancer registration at NICR, with the exclusion of pTa tumours (any grade) in our bladder cancer statistics, which explains lower cancer incidence. A regional audit of bladder cancers diagnosed in 2011 was recently completed in the Registry, which did not highlight any concern regarding data completeness.

Haematology:

The M:I ratio for haematological cancers during this period was 0.49. We believe that the detailed review undertaken for haematological registrations in 2012 has led to a more accurate measure of incidence for this year.

Completeness of dataset – patient demographics

Subsequent to the PIs being submitted, patient's address/ postcode has increased from 99.2% to 99.8% as we were able to use the Health and Care Number to find the missing information. Ethnicity has been problematic. The nearest we have is "country of origin" which we receive from our central data source. However the recording of ethnicity should improve in the future as it has now been incorporated within the hospital Patient Administration System (PAS).

Completeness of dataset – treatment information

Chemotherapy data is not available electronically from all health trusts which may explain the lower level of 22.5%. However, the introduction of the new Regional Information System for Oncology and Haematology (RISOH) will help with the completeness of treatment information.

Completeness of dataset – screening information

Our QARC has given us all the figures for screen detected cases, so we are fairly sure we are complete so believe the proportion of screen detected breast cancer for ages 50-67 of 49.7% to be accurate.

We will in earnest be working with QARC towards receiving full screening information for breast cancer to improve from the current 0% level.

Cervical screen detected data remains problematic for us to collect as the screening programme is not centralised as many GP surgeries carry out their own call/re-call system. It may be possible to give figures that are derived from the Cervical QARC call/re-call system and this will be explored in future years in order to improve from the current 0% level.

COMMENTARY FOR REPUBLIC OF IRELAND

General

Data presented for Republic of Ireland relate to cancer incidence in 2011, for all other submissions data are presented for cancer incidence in 2012.

Changes in Registrations

Male All cancers (C00 – C97 ex C44):

This follows the trend of an increase in male registrations every year since 1995. The average increase year on year since 1995 is 3.6%.

Female All cancers (C00 – C97 ex C44):

This follows the trend of an increase in female registrations every year since 1995. The average increase year on year since 1995 is 3.2%.

Melanoma Skin – males:

This is a trend that we have previously noted in our cancer atlas. The numbers here are quite small (416 registrations in 2011) so any change can look statistically large. Between 2009 and 2010 there was an increase of 17.8% in registrations (59 registrations) which would have an impact on the % change over the average of the three previous years. Below are tables showing the change by HB and age group.

Prostate:

Average year on year increase of 7% in prostate registrations since 2006 this is likely linked to the notes further down for prostate in Table 2I Mortality: Incidence ratios.

Cervix In Situ:

The National Cervical Screening Programme was implemented on 1st September 2008, between 2008 and 2009 there was a year on year increase of 40.4% in the number of Cervix In Situ registrations which also coincided with the “Jade Goody” effect. The increases in registrations between 2009 and 2010 and 2010 and 2011 were 3% and 9.8% respectively but the huge increase between 2008 and 2009 would have skewed the % change in registrations for 2011 based on the average of the previous three years.

Death Certificate Only rates (and zero day survivors)

All cancers (C00 – C97 ex C44) M & F ≥ 75 DCO rates:

There is a delay of 6-12 months between registration of a death and the date on which we are notified. The length of this delay reduces the response rate from hospitals and GPs to follow-up queries.

Zero day survival rates:

All cancers (C00 – C97 ex C44) M ≥ 75:

Many of these are hospice deaths where the original date of diagnosis was unknown. These were incorrectly coded to the date of death and have been corrected.

% Non-specificity of morphology codes for cases which are microscopically verified

Haematology:

There were 53 of these registrations; 10 had a morphology of M-9800/3 and the remaining 43 had a morphology of M-9590/3. Most of these were cases for which the histopathologist had given a morphology which could not be accommodated in the current ICDO3 coding.

Mortality: Incidence ratios

Prostate:

Although there is not an official screening programme for prostate cancer in this country since 2003 there has been widespread opportunistic screening which has led to the diagnosis of large numbers of potentially non-fatal prostate cancers. This has increased incidence to one of the highest in Europe while mortality is unaffected.

All cancers (C00 – C97 ex C44) M:

Mostly due to the number of prostate cancers

Completeness of dataset – patient demographics

Patients address:

The 0.4% of incomplete addresses that are blank or contain an unknown value and represent 82 addresses out of 20,250.

Date of death (where dead):

If the death has not been registered (this does not always happen) we have no way of identifying if the patient has died. At times we may receive information on an ad-hoc basis that a person has died from a research survey sent out to the patient etc but as this is not from an official source we are not guaranteed a DOD.

Basis of diagnosis:

The outstanding 2.7% of cases is where the basis of diagnosis field is blank or unknown. For many of these the only source of information is a hospital discharge record.

Completeness of dataset – treatment information

Prostate cancer – Hormone (% yes):

Of the 63% of prostate cancer patients that have had treatment: 27.5% have hormone, 23.5% have some form of prostatectomy without any hormone treatment, the remaining 12% have radiotherapy. Many patients in Ireland are managed by active surveillance.

COMMENTARY FOR SCOTLAND

Change in registrations

Variations in the % change in registrations across the UK and Ireland may reflect changes in the efficiency of ascertainment by some registries (skewing the UK and Ireland average), the play of chance, or genuine differences in incidence patterns.

We are not aware of any registration issues that may have affected recent trends in colorectal cancer in males, prostate cancer, or carcinoma *in situ* of the cervix. The incidence of colorectal cancer is now partly influenced by the evolution of the bowel screening programme. Detection of prevalent cases associated with roll-out of the national screening programme may have caused an increase in colorectal cancer incidence which is now reverting to previous levels (a small decrease has also been seen for 2012 in females). Prostate cancer is heavily influenced by the extent of PSA testing, which is known to be less extensive in more socio-economically deprived populations (Morgan RM, *et al*. *J Urol* 2013;190(4):1207-12). Northern Ireland also reports a recent small decrease in the reported incidence of prostate cancer. A decrease in cervix *in situ* disease is also difficult to interpret in the context of a cervical screening programme, but we are not aware of any shortfall in cases, and decreases are reported by some of the other countries. It is probably too early for this to reflect the impact of the HPV vaccine.

% Microscopically verified

Scotland's figure for lung cancer (68.2%) is lower than the UK and Ireland average (72.2%). It may reflect higher levels of co-morbidity and poorer performance status in Scotland, which would militate against microscopic verification (Grose D, *et al*. *J Thorac Oncol* 2011;6(3):500-9).

% Non-specificity of morphology codes for cases which are microscopically verified

Scotland's figure for prostate cancer is higher (4.4%) than the UK and Ireland average (1.6%). We believe that the term "carcinoma" (not otherwise specified) is used by some pathologists more freely than others – in these circumstances, our staff would not infer that these cases are adenocarcinomas, even though in practice they are most likely to be so.

Mortality: Incidence ratio:

Variations in mortality: incidence (M:I) ratios across the UK and Ireland may reflect, for example, changes in the efficiency of ascertainment or elimination of duplicate registrations by some

registries (skewing the UK and Ireland average), the quality of mortality data, the play of chance, or genuine differences in survival patterns.

We can think of no obvious explanation for the higher than average M:I ratios for cervical cancer in Scotland (0.38 vs 0.29). In the recently published EUROCARE-5 database, survival from cervical cancer is marginally higher in England than Scotland, but not different in a statistically significant sense. The higher than average M:I ratio for prostate cancer in Scotland (0.31 vs 0.24) might reflect an overall lower proportion of PSA-detected, indolent cancers in Scotland. The M:I ratio for bladder cancer is also higher than average in Scotland (0.58 vs 0.52), although similar to Northern Ireland (0.6). The M:I ratio for bladder cancer is particularly dependent on the extent of misclassification between invasive and non-invasive tumours, both in the cancer registry and in mortality records. This makes it difficult to compare results between cancer registries. Scotland also has a higher than average M:I ratio for haematological cancers (0.49 vs 0.46), although identical to Northern Ireland (0.49). It is difficult to think of an explanation for this relatively modest difference from the UK and Ireland average.

Completeness of the data set - screening information

Cervical cancer - % screen-detected for ages 25-67:

Although the figure for Scotland (43.4%) differs substantially from other registries, some registries have provided no data, and the figure for England (12.0%) seems implausibly low. For example, in a study in Southampton and South West Hampshire, the proportion of screen-detected cases of cervical cancer (invasive plus micro-invasive) in the age range 20-64 years was 43.5% (Herbert A, *et al*. *BJOG* 2009;116(6):854-9).

COMMENTARY FOR WALES

General

The Welsh Cancer Intelligence and Surveillance Unit (WCISU) has concentrated on improving stage at diagnosis to achieve the target of 70% with 2012 data. This has resulted in a change in the order of processing the various sources of data. All multi-disciplinary team staging data is added onto the WCISU database and then all unstaged cases were manually searched for staging from other sources. This resulted in an improvement in stage completeness but still lower than the target. WCISU normally validate routine cancer types but this year the unstaged cases were validated (over 6000 cases). However, this has had a detrimental effect on other indicators and some are slightly worse compared to previous years.

Stability of incidence:

Female lung cancer incidence has shown an increase over the past few years. Hence we believe this to be a true increase for females. There has been a decrease of 9.2% for female breast cancer in 2012 compared to the previous three years. The WCISU database was compared with the MDT data and with the breast screening database and numbers were consistent so we believe the figures to be true. In the past WCISU have not been able to record all cervix in-situ cases. For 2012 data, we now receive this information from colposcopy and so this should be accurate and hence the large increase in 2012 compared to previous years.

Death Certificate Only rates (and zero day survivors)

DCO rates have decreased in Wales in 2012 compared to previous years. However, there is one cancer type where the DCO rate was higher than the target, ill-defined sites. We hope that in future years the targets will be attained for these sites.

Zero day survival rates:

Zero day survival rates are high for ill defined sites and WCISU are currently investigating why this is the case and we are lower than last year.

% Microscopically verified:

All cancer sites do not attain their respective targets for microscopic verification. The figures are generally very similar to the previous year. WCISU are currently investigating those cases without microscopic verification.

% Non-specificity of morphology codes for cases which are microscopically verified:

There are a number of cancer sites that WCISU do not pass for this indicator: lung, breast in-situ, cervix invasive, colorectal, prostate, haematology and all exc NMSC (males and females). From July 2012 WCISU now code in ICD10 version 4. The implications are that the majority of haematology cases now come into WCISU with an unspecific morphology and so we have to code them as “80003” since there are no morphologies in ICD10 version 4 for haematology. This will also have an effect on all exc NMSC. WCISU is currently investigating the high rates seen for other cancer types.

Mortality: Incidence ratio:

The MI ratio for cervical cancer is lower than the target because there has been a large decrease in the number of deaths in 2012 compared to previous years. This is probably due to the decrease in incidence that was seen in Wales between 2010 and 2011.

Completeness of the dataset - demographics and diagnostic details

The completeness of ethnicity is still very poor in Wales due to the only source at present being the Patient Episode Database for Wales (PEDW) and this is rarely completed.

It is difficult to comment as to why the proportion of cases where the site of primary growth may be too low. Our main sources of data are PEDW, Canisc and pathology and WCISU colleagues are currently investigating if this is a coding or training issue.

WCISU are currently investigating the cases that have unspecific morphologies to determine any possible reasons as to why they are so high. Basis of diagnosis is lower than last year at 90.7% and WCISU is currently investigating these cases to ascertain the reasons behind these high rates.

Completeness of the dataset - treatment information

The WCISU do not yet receive radiotherapy information for all Wales, hence the lower figure than expected. We have just started collecting hormone therapy information, however, this information is limited at present due to the source of data used, hence the low figure. We believe that since the hormone treatment figures are very low compared to other registries then this information for cancers such as prostate cancer and breast cancer has resulted in overall low treatment information for these cancers. WCISU are currently examining the treatment results for all cancers in ages 0-24 years.

Completeness of the dataset - site specific information for breast cancer

The completeness of grade, size, number of positive nodes and NPI is slightly lower than in previous years and have not attained their relevant targets. WCISU are currently examining those cases without a NPI score to see if we can locate a NPI for these cases.