Commentary on UKIACR performance indicators 2014 registrations

OVERVIEW

England

The English National Cancer Registration and Analysis Service (NCRAS) is proud to submit a single set of performance indicators (PIs) for the whole of England for the third year. The 2014 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.

Ireland

Registration in Ireland remains predominantly manual, with treatment and staging data being extracted from paper medical records up to a year following the date of diagnosis. Due to staffing shortages, there are backlogs of registration in some of the larger hospitals, resulting in late recording of data, particularly stage and treatment. Access to electronic data has speeded the process of case ascertainment, but has had little impact so far on timeliness of stage of treatment data. There are also, however, delays in processing electronic data, also due to staff shortages. There are no centralised health service systems for sharing of electronic histopathology data, hospital discharge data or death certificates, so these must be sought from each hospital individually.

N. Ireland

This year saw the Health and Social Care (Control of Data Processing) Bill achieve Royal Assent on 11 April 2016. This bill provides framework to enable use of health and social care information for health and social care purposes which are in the public interest. The details will be in subordinate legislation and we expect regulations to be drafted and consulted upon before being scrutinised and debated by the N. Ireland Assembly. This should clarify the legislation for cancer registration here.

The Registry, which is located in Queens University Belfast, and funded by the Public Health Agency received extra resources to enhance cancer staging and this was instrumental in the high level of staging achieved, We have used the Praxis cancer registration system since the start of registration in N. Ireland and have found it a stable system with good features of electronic data matching. However it does not facilitate all the new data items that we aim to record on each patient and so we are seeking new solutions. Access to the Labcentre pathology system was acquired this year and has been of great benefit to the Tumour Verification Officers (TVOs) with regard to tumour staging. NICR now receive pathology reports for private patients from Spire Pathology Services, ensuring more timely registration of private patients. Increased investment in TVO staff has enhanced tumour staging greatly and also further forged the partnership between the Northern Ireland Biobank and the Registry, with a TVO partly funded for Biobank studies.

Wales

The Welsh Cancer Intelligence and Surveillance Unit (WCISU) has demonstrated year-on-year improvement across key indicators up to and including 2014 registrations. We have managed this despite working within the confines of the current outdated informatics system. This is a credit to the dedication of the WCISU cancer registration, coding and classification and informatics teams, supported by the rest of the unit.

Our existing cancer registration IT system has reached the end of its useful life. Following discussions with Public Health England (PHE) National Cancer Registration and Analysis Service (NCRAS), Public

Health Wales has been successful in negotiating the procurement of a Welsh branded version of ENCORE used by NCRAS in PHE. Both parties will work in collaboration to migrate to this new system during 2016/17, aiming to 'go live' in 2017/18 at the latest.

The implementation of ENCORE in Wales will be the enabler for WCISU to exploit new datasets. ENCORE will provide facilities for new data linkage opportunities such as Systemic Anti Cancer Treatment (SACT) data, Radiotherapy Dataset (RTDS), e-prescribing and GP data, for example, which will also facilitate core cancer registration. We are moving from the existing coding classification ICD 10 to the more appropriate and specific ICD-O-3 classification used by all the other UK and Ireland registries. This will allow greater comparability and detail.

REGISTRATIONS

England
2014 saw a reversal in the previous rising trend in the overall number of all invasive cancers (excluding non-melanoma skin cancers) with a slight fall. This fall is driven mostly by a dip in the number of prostate cancers. Investigations into this suggest that it is not that the 2014 figure is surprisingly low, but that the 2013 figure was surprisingly high (as we commented on last year). This may be in part due to data quality - 2013 was the first year of the COSD data feeds and there was the potential for over registration. The launch of the National Prostate Cancer Audit (April 2014) and increased availability of remote access to Trust systems has enabled improved validation of clinical cases.
The decrease in colorectal cancers first commented on last year continues to be seen in males, but numbers appear to have stabilised in females. There are no known data quality issues around these cases, and it is believed this may be a real trend. Further investigation into possible effects of the bowel screening programme on colorectal incidence would be helpful.
In situ breast cancer also continues to rise very rapidly. It is now unlikely that last year's coding changes could explain this entire rise.

N. Ireland
1. Lower GI – there was a significant decrease in the number of females diagnosed in N. Ireland in 2014 with cancer of the lower GI, similar to that noted in England and Scotland. The exchange with the regional screening service, QARC, was not completed due to staff issues within QARC, and may identify cases missed in the screening population.
2. Lung - there was a significant increase in the number of females diagnosed in N. Ireland in 2014 with cancer of the lung, as noted also in England. This is in keeping with an increasing trend as reported previously.
3. Cervix - there was a significant decrease in the number of females diagnosed in N. Ireland in 2014 with cancer of the cervix. Incidence of cervical cancer in N. Ireland fluctuates year on year, ranging from 72 to 127 cases annually. The annual exchange with QARC for cervical cancer has been completed, therefore no further cases will be identified from screening. The reduction may reflect a settling after an increase observed coincident with Jade Goodie being diagnosed several years previously.
4. Other invasive cancers - there was a significant increase in the number of females diagnosed in N. Ireland in 2014 with "other invasive cancers". This is likely to variation in small numbers as it relates to an increase of only 11 cases on the previous year.
5. Other tumours - there was a significant increase in the number of males diagnosed in N. Ireland in 2014 with "other tumours". However this relates to about 90 additional cases, which in in keeping with the year on year fluctuation within the registry. There was no individual site within this group that exhibited a marked increase.

Scotland

Overall stability (-0.6%) is similar to the UKIACR average (-0.4%), although this conceals more striking changes for some specific cancers. Of particular note, there has been a sizeable increase in incidence of invasive cervical cancer between 2013 (318 cases) and 2014 (384 cases), an increase of 21%. There is not an obvious explanation for this. Although we have recently obtained access to the Scottish Cervical Call-Recall System (SCCRS) database as a supplementary source (for 2014 incident cases onwards), this seems unlikely to be the explanation because we already received pathology data from across Scotland (and >98% of cases are microscopically verified). Furthermore, the percentage change in CINIII (+5.0%) is very similar to the change (+5.3%) reported in England. The increase in invasive cervical cancer is not confined to a single NHS Board (although there is considerable variation between Boards – with incidence staying the same or decreasing in some Boards). Over the last five years, there has been no obvious change in the distribution of cases by a range of characteristics, including age group, stage, MV status, DCO status, and % adenocarcinoma. Previously published data show considerable variation in numbers of cases of invasive cervical cancer from one year to the next.

Ireland

There was a big fall in the number of all cancers other than NMSC in the 0-24 age group. At the time of the data extract data had not been received from the main childhood cancer hospital. These cases have since been added and bring the figures up to what they should have been.

As with the previous year there is a continuing increase in melanoma incidence. This is matched by an increase in mortality and is considered to be a real trend.

Large falls were noted in cancer of the cervix, both invasive and in situ. The national cervical cancer screening programme began in late 2008 and it seems that incidence rates are now beginning to fall, possibly as a result of early detection, but more likely as the incidence surge which accompanied the early days of the programme is ending. There are delays in reporting of in situ cancers, and the figures 600 in situ cases for 2014 were still outstanding when the data extract was made.

Wales

All malignancies are increasing year on year in Wales.

Some cancer types show a statistically significant increase in the number of cases in 2014 compared to the average of the previous three years. It is recognised that there is an increasing trend for melanoma in men over the past few years and therefore consider this to be a real increase as seen in other UK countries. The same is true for female breast cancer and some other cancer types highlighted in the report.

DCOs

England

The registry continued the downward trend in DCO rates established last year, and is now proud to announce that we are not only meeting the 2% target once more, but exceeding it with a rate of 0.9%. This improvement in quality is a testament to the hard work of registration staff, to the new QA reports, and to the role of the PIs in focussing our attention on the issue.
NCRAS has developed an automatic process to register the majority of non melanoma skin cancers (NMSC) without the need for manual intervention. This has improved the quality of the completeness of our NMSC data, and improved registry efficiency. We are pleased that numbers of NMSC are now back up to their usual levels after the migration.

Ireland

The DCO rate is above UKIACR average overall especially high in the oldest group, many of whom died in nursing homes and are difficult to follow up due to change of GP and change of address from that given at registration. Zero survival is high for the same reasons as the high DCO rate.

The high DCO rate is due to the fact that there is no central system for clearance of death certificates, which must be individually followed up with the certifying doctor and then by the registry if the hospital of treatment can be identified. GPs delay in responding and some do not respond, so a hospital of treatment cannot be identified. Some 2014 death certificates were still being traced when the data extract was made.

N. Ireland

The percentage of DCO cases for Northern Ireland was lower than the UKIACR average in 23 of the 26 reported tumour groupings. This was also the case for the percentage of zero survival cases (persons). For all invasive cancers excluding NMSC, the % DCO for NI was 0.68% (UKIACR average 1.01%), whilst the % of zero survival for NI was 0.90% (UKIACR 1.51%).

Scotland

Consistent with previous years, Scotland has the lowest proportion of death certificate only (DCO) cases (0.3% compared with the UKIACR average of 1.0%).

Scotland also has the lowest proportion of zero day survivors (0.6% compared with the UKIACR average of 1.5%).

Wales

We continue to maintain our DCO rates below the target but acknowledge that the rates are higher than the majority of other UK countries.

Nevertheless, DCO rates are particularly higher than other UK countries and the UKIACR average for older age groups, with probable statistical instability for younger age groups. There may be a systematic error occurring because the DCO rates appear higher for most cancer sites, although several stand out, such as head and neck, lung, breast, prostate, kidney, bladder and CUP. The statistical team will explore the DCO profile in Wales later this year to understand any potential issues that may relate to cross border patient pathways and the associated gap in the data received by WCISU. On the other hand, the DCO rate may be truly high in the population given that Wales has a known relatively late stage at diagnosis across several cancer sites, and poor survival outcomes.

Late registrations

Scotland

The figure for Scotland (2.5%) is slightly higher than the UKIACR average (2.2%). It is difficult to determine an 'ideal' figure for this indicator. For example, it is preferable to capture detailed information on late registrations than to have them assigned to later years as death certificate only registrations, or to fail to capture cases of indolent cancer.

PATIENT DATA

Ethnicity

England

There has been a clear improvement in the ethnicity data, rising from 57% in 2012, via 80.4% in 2013 to over 94% in 2014.

N. Ireland

Ethnicity data has only recently been accommodated as a field in the hospital administration field and is as yet not well completed and so is not available from source data for the Registry.

Scotland
Average of core patient information complete for Scotland (95.4%) is low because completeness of ethnicity was 63.5% which reduced the average percentage. All other items contributing to this indicator are close to 100% complete.

Wales
The lack of ethnicity data has been a long standing issue for Wales and acknowledge that we now have to explore alternative ways of collecting this data. It is proposed to explore more innovative ways to source this data in the future such as access and linkage to the patient experience survey in Wales and GP data.

CANCER DATA

Microscopic verification

Ireland
The relatively percentage of microscopically verified cases reflects delays in a few hospitals in provision and processing of hospital discharge records, which are the main source for ascertainment of non-microscopically verified cases. These are currently being processed.

N. Ireland

Levels are within the expected range.

Scotland
The figure for Scotland (84.8%) is similar to the UKIACR average (85.7%). Obviously, the proportion of microscopically verified cases depends to a large extent on case-mix – for example, countries with a higher proportion of lung cancer cases might be expected to have a lower proportion of microscopically verified cases.

Scotland has the lowest proportion of non-specific morphology codes recorded (1.5% compared with the UKIACR average of 3.2%).

Wales
Microscopic verification rates on the cancer registry are lower in Wales compared to other UK countries and the UKIACR average. Microscopic verification is low for almost all cancer types, with some being very low. This suggests that there has been a systematic problem in registration or data sources. This is likely to improve significantly as pathology reports will achieve primacy in cancer registration within our new ENCORE system. In the meantime work is ongoing with data sources to ensure the correct basis of diagnosis is assigned.

Staging

England
There are clear success stories in the 2014 data. The dramatic improvement in staging rates for invasive cancers has continued: after meeting the 70% target last year with 70.8% of the 2013 data staged, 76.7% of the 2014 cancers are now staged - a far cry from the 51% for 2011 only 3 years ago. Within this, the NCRAS has continued to record stage rates of above 85% for the four main cancer

sites of breast, colorectal, lung, ovarian and prostate, while also improving staging data for other cancer sites.

Ireland

The above average proportions of late registrations and unstaged cases and the low treatment percentages are due to the fact that registration was not complete for 2014. We currently do not have procedures in place to assign a TNM summary stage in TNM7.

N. Ireland

The high level of staging submitted by N. Ireland was possible due to additional staff. The Public Health Agency for NI has invested in pathology support, in the form of 2 part-time pathologists who each work on staging cases for 2 hours per week. There were also 2 additional Tumour Verification Officers employed for 6 months which boosted staging greatly. Without these resources, a figure of 80% would not have been achieved.

Scotland

Since last year, following on from publication of further cancer audit/quality performance indicator (QPI) data sets in Scotland, we have added some cancer sites for which we are seeking to collect staging information. This has led to an increase in the proportion of staged cancers, although our proportion (51.3%) is still below the UKIACR average (63.5%). (Note that staging data in Scotland are also collected for selected cancers via cancer audit). Further sites have been added to next year's cancer registry data. On the basis that staging information for less than 70-80% of cases at a given anatomical site cannot really contribute to any meaningful analysis, we have concentrated on trying to maximise completeness at specific sites. For the main sites and/or those cancers for which there are screening programmes, staging completeness was as follows:

Cancer site	Scotland	UKIACR Average
Lower GI	76.0%	77.7%
Lung	78.5%	75.6%
Breast	83.3%	83.0%
Cervix	94.3%	73.3%
Prostate	69.8%	73.8%

As has been pointed out in the past, completeness of recording a data item is no guarantee of data validity. For example, accurate staging of breast cancer is crucially dependent on the pathologically determined numbers of positive axillary lymph nodes. Clinical assessment of nodal status is notoriously unreliable, with false negative and false positive rates of around 33% (Specht MC *et al*, *J Am Coll Surg* 2005;200(1):10-4). While this performance may be improved by imaging, pathological examination remains the 'gold standard' for evaluating axillary lymph node status (Cserni G, *J Clin Pathol* 2000;53(10):733-41; Rahbar H *et al*, *Curr Probl Diagn Radiol* 2012;41(5):149-58). Consequently, levels of completeness of recording breast cancer stage should be considered alongside the completeness of recording of pathologically determined numbers of positive axillary lymph nodes. Unfortunately, the percentage of breast cancer cases with known number of positive nodes has not been included as an indicator this year, but last year, the proportion was 83.1% in Scotland (compared with a UKIACR average of 77.9%).

Wales

There has been a dramatic improvement in registry staging completeness over the last few years despite many changes in working practices. We are now just under four percentage points away from achieving the target of 70% for all malignancies. Over the past three years we have improved from 53% for those patients diagnosed in 2011 to nearly 67% for those diagnosed in 2014. Whilst we still trail N. Ireland and England for all malignancies, we are now comfortably above the UKIACR

average. This has been the result of a concerted effort of our registration team, improved team management and leadership, and better use of source data. Whilst improvement is apparent, there is still scope to improve source data as acknowledged by leading clinicians.

It is important to note that we are exceeding 80% for stage completeness for many of the most common cancer types such as colorectal, lung, kidney and malignant melanoma. With the implementation of ENCORE and its associated reporting facilities WCISU will be able to provide data completeness feedback real time to health boards/multi disciplinary teams in Wales which we are not able to implement at present. It is anticipated that this will drive the increase in data completeness and quality received for key data items such as stage.

Grade

England
The information provided by the new PI on the recording of grade information is valuable. It is reassuring that although this has not been measured before the overall percentage is very similar in four of the five countries. This indicator allows us to see areas where the English data is exceptional and should be promoted (such as the grade data on our breast cancers) and has also highlighted areas where we may be able to drive up data quality. It will be good to work with the other UKI countries to interpret these results and share best practice.

Scotland
Scotland has the highest proportion of cancers recorded with a known grade of differentiation (56.2% compared with the UKIACR average of 47.6%).

Wales
The introduction of this new performance indicator on recording of grade has enabled WCISU to highlight the shortfall in completeness of grade information across all tumour sites. Despite this being collected by multidisciplinary teams this data is not flowing successfully into the registry. Our action plan to address this for subsequent years consists of three main areas; new registration system, review and amendment of existing data feeds, provide data quality and completeness feedback to MDTs to raise awareness and identify training needs.

Other cancer variables

Ireland
Basis of diagnosis and hospital of diagnosis are below average due to delays in registration.

Scotland
Average of core tumour information complete: The figure for Scotland (98.3%) is the highest of all the UKIACR nations (UKIACR average 96.6%).

Diagnosing hospital known: the figure for Scotland (94.0%) is lower than the UKIACR average (95.8%) because we were asked to exclude GP practices where some skin cancers were diagnosed and excised.

TREATMENT

England
We welcome the new PIs. The focus on the availability of patient pathway information such as where the patient was diagnosed, and where and when their treatment took place, will drive up quality and enable us to do more powerful analysis. The inclusion of treatment decisions such as

watch and wait / active monitoring and palliative care also helps us to understand the full patient pathway. The percentage of English cases treated is greater than that in other UKIACR countries. The NCRAS feels that this may be because in England we are able to record treatment such as active monitoring, watch and wait, and palliative care, as well as the conventional categories of surgery, radiotherapy and chemotherapy.

The tight timescale for the data freeze (the year was finished in December 2015, and QAed in January 2016, before being frozen for the PIs at the end of January 2016) means that we have not completed all projects that involve linkage of external datasets. Because of this we do not yet have drug name/regimen for chemotherapy (which will come from linked SACT data) or fractions/dose for radiotherapy (which come from linked RTDS data). We expect to have these in the next few months.

Ireland

The treatment percentages are very low; especially chemotherapy, due to delays in registration. Unlike the other countries. Ireland classified all patients as either treated or not treated; no cases were classified as "other.

N. Ireland

Wait/Active monitoring (WW/AM) is not part of the core dataset recorded by the NICR but as it is a field on the Cancer Patient Pathways System (CaPPs), which NICR has electronic access to, it could be collected in the future.

Palliative Care (PC) is not part of the core dataset recorded by the NICR but is a field on CaPPs. We would be interested to know what sources other Registries use to identify palliative care, for example, is place of death as hospice identified from death records valid? Such data sources would need to be validated before use.

Scotland

The figure for Scotland (70.9%) is similar to the UKIACR average (70.3%), although there may be differences in the definition of what constitutes treatment between the contributing cancer registries.

Wales

Compared with other countries, a considerable amount of treatment data appears to be missing in the registry. This makes interpretation of the treatment/no treatment and stages 1 and 2 receiving treatment data difficult. Whilst issues with the data are likely to be the main explanation, we know from certain Healthcare Quality Improvement Partnership (HQIP) national audits that, for some cancer sites at least, the proportion of patients receiving treatment appears to be low compared to England, including for early stage disease. With the new emerging radiotherapy dataset and SACT dataset in Wales we anticipate some improvement in these treatment indicators in future years.

SCREENING

England

We are very excited that 98% of the colorectal cases in 2013 now have a screening history. This is the first time these data, linked to cancer registration data, have been available in the national registry dataset. We are pleased to see Scotland and N. Ireland can also now provide colorectal screening histories, and would welcome UK wide analysis of these data. We welcome the move to more timely PI reporting on the 2014 screening data, but were not able to complete the full screening linkage before the PI deadline.   This work is ongoing, and we expect the final completeness figures to be as least as good as the 2013 figures.

N. Ireland

Bowel screening information was unavailable for 2014 due to a maternity leave absence within QARC. NICR will receive this information on their return.

Scotland

1. Breast Screening: There is considerable variation between the countries. Scotland's figure of 46.4% of breast cancers detected by screening in the age range 50-64 years is not too different from the UKIACR average (40.5%) but differs considerably from the figure for England (11.1%).

2. Bowel Screening Data: Again, there is considerable variation between the countries (although data are not available for all the UK countries). Scotland's figure of 28.9% of bowel cancers detected by screening in the age range 60-69 years is not too different from the UKIACR average (22.7%) but differs considerably from the figure for England (17.5%).

3. Cervical Screening Data: Once again, there is considerable variation between the countries (although data are not available for all the UK countries). Scotland's figure of 54.4% of cervical cancers detected by screening in the age range 25-60 years is very different from the UKIACR average (30.4%) and from the figure for England (8.8%). In an era when uptake of cervical screening may have been a little higher, a study in Southampton and South West Hampshire found that 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).

Wales

A change to WCISU business processes introduced this year relating to screening data has shown a large improvement in the proportion of breast cancer registrations with a full screening history. Whilst this is excellent news, further work is needed to reach the levels of Scotland and N. Ireland, when interpretation of the relatively high proportion of screen detected cases will be more meaningful.

The bowel screening programme in Wales is now well established. The age range and screening interval is the same as for England – people aged 60-74 years whereas in Scotland it is 50-74 years. This is the first year that we have received bowel cancer screening information and we shall continue to build on this with the implementation of new systems. We accept more complete screening history information is needed to accurately record and interpret the proportions that are screen detected for bowel cancer.

CONCLUSIONS

England

Overall, these Performance Indicators highlight the high data quality of the 2014 data available from the English National Cancer Registration and Analysis Service. These data demonstrate that the service is continuing to improve because of the commitment, expertise and teamwork of our staff.

Ireland

These performance indicators cover a wide range of data. Some are relevant to the performance of the cancer registry, but others (e.g. treatment percentages) are dependent of health service activity outside the control of the cancer registry. We recognise that, due to the very different health service organisation in Ireland, and the place of cancer registration within it, our timeliness suffers by comparison with the four UK registries. We are working with electric sources to try to improve timeliness, but must reconcile this with the growing demand for more detailed data. We hope that an increased emphasis on information, which is expected to be in the new national cancer strategy, will pave the way to a better resourced and more timely cancer information system for Ireland.

N. Ireland

The NICR welcomes the results of the PIs, which highlight the high quality data held within the Registry. We appreciate the opportunity to compare data with our close neighbours as this encourages ongoing improvement in data quality.

Wales

Through the commitment and innovation of WCISU's team, leading to better registration practices and reorganising the use of data sources, there has been a demonstrable sustained improvement in key indicators. This has occurred despite working within the confines of the current outdated informatics system and inadequate legacy data sources. With WCISU's adoption of the new ENCORE cancer registration system during 2016/17, along with further improvements in registration practices, new data sources and linkage, and a change in coding, we anticipate our journey of continual improvement in key performance indicators to progress at pace.