United Kingdom and Ireland Association of Cancer Registries (UKIACR)

Performance Indicators 2018 report

20 June 2018

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Introduction

All five UK and Ireland cancer registries extract data relating to a number of performance indicators to allow comparisons of the timeliness, quality and completeness of their data. This information is collated centrally and an annual report is published. For the 2018 report, Wales and Ireland have not participated due to delays in 2016 registrations from implementation of new systems in their respective countries.

The measures are broken down by cancer type and some indicators measured are as follows:

- Stability of incidence in the current year compared to the average of the three previous years
- Completeness of data items such as known date of diagnosis, date of birth, identification number, ethnicity and tumour behaviour code
- Completeness of screening category for breast, bowel and cervical cancers
- Completeness of stage at diagnosis by cancer type and morphology
- Proportion of death certificate only (DCO) cases
- Proportion of patients whose morphology code is non-specific, proportion of microscopically verified cases, the mortality to incidence ratios
- Proportion of tumours that have any treatment where treatment would be expected (i.e. childhood, early stage)

This report accompanies the collated tables for this set of performance indicators and details the commentaries supplied by cancer registries in the UK and Ireland for various indicators where the value was below the target or not in line with other registries as well as detailing the success of particular performance indicators.

Two averages have been calculated for the overall UKIACR average, one based on the average of the three UK countries and another based on the population of the three countries as a whole. The latter is biased towards the English results due to England having a much larger population than other UK countries.

UKIACR country averages are quoted in this report throughout (unless otherwise specified).

Commentary for England

The NCRAS registration team again completed their routine processing in October allowing the quality assurance team time to run their checks in November. Therefore, the data on 2016 diagnoses used in this report were extracted from an analysis snapshot taken at the beginning of December 2017; two months ahead of the UKIACR submission schedule.

Although the overall staging percentage increased by 1.5% on last year to 81.9%, the rate of increase is beginning to plateau. Improvements having been made for the major sites, we are now working on the less common ones.

Our DCO rate continues to fall as does the proportion of zero day survivors, although both are higher than those reported for Scotland and Northern Ireland. From the detailed breakdown the main differences are in older patients, HPB and CUP cases.

We reported last year that the move to PHE and subsequent changes in personnel and service configuration had disrupted routine screening data exchanges. Resource at a senior level was made available to address these issues. A national cervical screening exchange is being discussed. Whilst the details are still to be formalised, screening data were received for 2015 diagnosed cases. In November 2017 we added bowel screening categorisations for 2006 to 2015 diagnoses and are awaiting a further exchange for 2016 diagnoses.

NCRAS have been working hard to collect full information on drug name and regimen on all cancer patients, as part of the SACT dataset. This information was not fully linked and processed by the time the PIs were calculated, and so is reported at 0%. However, this work is ongoing, and drug names and regimens will be available for analysis for 2016 cases, and are expected to have a high completeness.

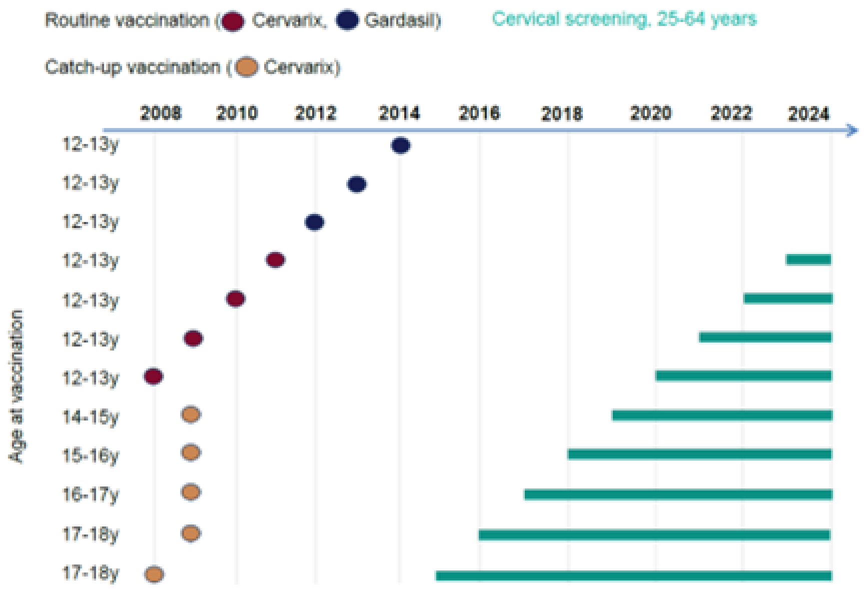
Stability of incidence has been affected by the migration to a single system as well as the introduction of the Cancer Outcomes and Services Dataset (COSD) in 2013. Trend analyses suggest that a more stable position will be obtained when 2013 diagnoses cease to contribute to the calculation of the expected incidence. However, there are two sites which we believe require a specific comment: Head and Neck and Cervix in situ.

The incidence of Head and Neck cancer is increasing for England whilst decreasing in both Scotland and Northern Ireland. We are confident in these figures as the training given to Registration teams enables them to accurately record the site and stage of the tumour. When we look at a breakdown of these cases we find that the increase is primarily in oropharyngeal cancers; in particular the tonsil and base of tongue sub-sites. Currently, we do not record HPV status so we cannot confirm whether the increase is associated with HPV infection (HPV testing has been recommended for oropharyngeal cancers (NICE guidelines 2016)). However, we are planning to collect HPV status for oropharyngeal tumours diagnosed from 2018 onwards.

The incidence of CIN3s in 2016 is significantly lower than the average for the previous three years (2013-2015). However, the numbers of CIN3 increased between 2012 and 2015. The most likely reason for this is the effect of the introduction of human papilloma virus (HPV) triage and test of cure into the screening programme between 2012 and 2015. This major change increased referrals to colposcopy during this period after which referrals were expected to fall again. The increased colposcopy activity is likely to result in an increase in cases of CIN3 being detected. This will be skewed towards younger women as they are more likely to have cervical abnormalities and to be high risk HPV positive.

It is also possible that the continuing decline in cervical screening attendance rates, predominantly in younger age groups, and the effect of women coming into the programme who were vaccinated against HPV when they were 16-18 years of age may be starting to reduce rates of CIN3, although the numbers in this vaccinated cohort were relatively small. The following chart indicates that in 2015/6 women that have been vaccinated will be part of the screening programme - the green bars showing when the cohort would be included in screening. In the case of vaccinated women, it is too early to be sure of the impact.

Figure 1. HPV vaccination cohorts and scheduled cervical screening in England



(https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/412264/HPV_Vaccine_Coverage_in_England_200809_to_201314.pdf, p12)

Looking at the England data by age group demonstrates a decrease in incidence in the 20-29 age group as would be expected given the above, following the observed increase between 2013 and 2015. This decrease is consistent across the different NCRAS offices.

	Diagnosis Year							**2016/Average (2013 to 2015)%**
Age group	**2010**	**2011**	**2012**	**2013**	**2014**	**2015**	**2016**	
Under 20	40	21	12	13	10	9	7	66%
20-29	11978	12640	12969	14548	14634	13605	11332	79%
30-39	7789	7789	7875	7742	7868	7941	7411	94%
40-49	2922	3128	3031	2781	2735	2736	2442	89%
50-59	706	745	781	755	870	785	800	100%
60-69	239	281	296	275	213	246	231	94%
Over 70	40	52	55	65	60	48	41	71%
Total	23714	24656	25019	26179	26390	25370	22264	86%

Some decreases were also observed in older age groups which suggest that there may be issues of data provision. A member of the NCRAS Data Liaison team is leading a project to investigate potential shortfalls in data provision with colleagues from across the country. However, the decrease in incidence is more marked in the younger age groups.

It should be noted that NCRAS uses an automated process to record non-melanoma skin cancers. This enables all cases to be captured. The process records treatment and staging data from COSD submissions. As COSD only mandates submissions for patients being referred to MDT, treatment and staging data are not available for the majority of non-melanoma skin cancers.

Overall, high values for staging (81.9%), average completeness of core patient (99.1%), tumour (97.4%) and treatment information (88.9%) have been maintained. Delivering this standard year on year is a tremendous achievement.

Commentary for Scotland

Stability

Overall stability for Scotland is -4.1%. One contributing factor to this may be the lack of a radiotherapy data stream. The Scottish Cancer Registry received data extracts of Scottish radiotherapy data from NATCANSAT, but this has now ceased. Work is underway to receive this data from other sources.

Registry creep

The figure for Scotland (3%) is the highest of the three UKIACR registries that have been reported this year. As noted last year, it is difficult to determine an ‘ideal’ figure for this indicator. 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.

Staging

The proportion of staged cancers in Scotland has increased from 60.8% in 2015 to 67.2% in 2016. Since last year, we have added some cancer sites for which we are seeking to collect staging information. Although there are currently no plans to collect stage for further sites, cancer registration staff now have access to cancer audit data, which should help to increase the completeness of staging information next year. 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	73.6%	84.8%
Lung	91.7%	93.2%
Breast	84.8%	91.4%
Cervix	95.9%	95.6%
Prostate	84.3%	89.4%

Average of core patient information complete

The figure for Scotland (96.3%) is low because completeness of ethnicity was 70.1% which reduced the average percentage. Most other items contributing to this indicator are close to 100% complete.

Average of core tumour information complete

The figure for Scotland (96.5%) is similar to the UKIACR average.

Diagnosing hospital known

The figure for Scotland (93.5%) is higher than the UKIACR average.

DCO rates

Consistent with previous years, Scotland has the lowest proportion of death certificate only (DCO) cases (0.2% compared with the UKIACR average of 0.4%).

Zero day survivors

Scotland has the lowest proportion of zero day survivors (0.6% compared with the UKIACR average of 0.9%).

Microscopically verified

The figure for Scotland (83.9%) is similar to the UKIACR average (84.8%). 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.

Non-specific [morphology] codes

Scotland has a low proportion of non-specific morphology codes recorded (1.2% compared with the UKIACR average of 1.3%).

Grade [of differentiation]

The proportion of cancers recorded with a known grade of differentiation is slightly lower in Scotland (58.6%) than the UKIACR average (61.1%).

Treatment

The figure for Scotland (69.5%) is similar to the figure for last year. Only England and Scotland submitted figures for this measure, so it is difficult to comment further. For surgical treatment, more data will be available next year on patients treated with palliative surgery.

Breast Screening Data

Scotland’s figure of 51.4% of breast cancers detected by screening in the age range 50-64 years is the highest of the three registries included in this report.

Cervical Screening Data

Scotland’s figure for cervical cancers detected by screening in the age range 25-60 years was 45.3%. This is lower than the previous year (54.4%). Only England and Scotland submitted figures for this measure, so it is difficult to comment further.

Bowel Screening Data

Scotland’s figure of 27.1% of bowel cancers detected by screening in the age range 60-69 years is similar to the figure in 2014. Only England and Scotland submitted figures for this measure, so it is difficult to comment further.

Commentary for Northern Ireland

Overview

The N. Ireland Cancer Registry (NICR), located in the Queen's University Belfast, is funded by the Public Health Agency (PHA) for Northern Ireland (NI). Like all Cancer Registries our work uses data provided by patients and collected by the Health service as part of their care and support. We have been undertaking changes to improve the PRAXIS cancer registration system used by the NICR. These upgrades to the system will improve how we process cancer registrations. Unfortunately, the improvement works have also resulted in delays in processing registrations for the 2016 dataset.

This has been a difficult year for the NICR's external partners in terms of the transfer of cancer notification data. Due to coding errors within the General Register's System death certificate data transfer was significantly later than usual. Also, due to pressures within our National Health Service, PAS records were transferred to the NICR late. This has resulted in longer times to process our cancer registration data. Screening data was also transferred late for the snapshot date of 31/01/2018.

There have also been significant changes to systems providing Northern Ireland's treatment data to include:

- The North West Cancer Centre began treating patients from March 2017. This is Northern Ireland's second cancer centre and is delivering chemotherapy and radiotherapy to cancer patients on a cross border basis.
- Nationwide in April 2017 Northern Ireland has implemented a new oncology system called RISOH (Regional Information System for Oncology and Haematology system) to replace the older Clinical Oncology Information System (COIS). This new RISOH system is expected to yield much more detailed treatment and clinical data extracts.
- The Belfast Cancer Centre has been upgrading its radiotherapy data software, including integration of the Health & Care Number index which will lead to easier data linkage.

These changes have led to increased pressures in the local health services in collating and transferring treatment data to the NICR (in particular radiotherapy treatment data). We are currently working with the respective teams in order to resolve this.

Registrations

There was an increase in the total number of invasive cancers excluding non-melanoma skin cancers (NMSC's) in 2016 compared to the 2013-2015 total average. There was no statistically significant change in the total invasive cancers (ex NMSCs) in males. However, by comparison there was a statistically significant increase in female cancers. This change is mainly observed in lung cancer where in 2016 for the first time in our history of the NICR there were more incident lung cancers diagnosed in females compared to males. This increase in registrations is most notable in the 60-79 age group.

The NICR also noted a continuing statistically significant increase in non-melanoma SCC's diagnosed in males in both 2015 and 2016. This may be associated with a skin cancer awareness campaign, launched by the PHA for NI in 2015, which was targeted at outdoor workers (tending to be predominantly male).

A decreasing trend in colorectal cancer has been noted since 2013 which may be linked with the screening program; similar trends were seen in Scotland.

In 2016 there was a significant drop in cervical insitu lesions registered. A decrease was observed in both England and Scotland, and an overall average decrease of 13.9% compared to 20.6% in Northern Ireland. This may be due to changes in screening pathway protocols, screening uptake, and potentially due to seeing the effects of the HPV vaccination programme in Northern Ireland. Further investigation and longer follow-up is required.

Stability

Registry creep has fallen from 2.5% in 2017, to 2.1% in 2018. The NICR is continuing to try and improve this through better access to electronic patient information systems.

DCO rates

The NICR continues to achieve a DCO rate well below the 2% target across each of the tumour groups, with a level of 0.4% for the combined group of all registrations. However, the 2% target was not met for cancer of the unknown primary (3.6%). Higher levels are not unexpected in this tumour group as because of the short survival time it may not have been possible to fully investigate to enable an accurate diagnosis.

Zero Day Survivors

At 0.7%, the percentage of zero day survivors for NI was within target. One exception was cancer of unknown primary (4.6%) and patients aged over 80 (2%).

Microscopic Verification

The NICR had a high level of microscopic verification (85.3%). There was a decrease in microscopic verification rates in Brain and CNS patients from 69.3% in 2015 to 60.6% in 2016, this may represent a change in the patient pathway and the NICR is currently investigating. The percentage of non-specific of morphology code was similar to other jurisdictions. A higher level was flagged for Cancers of Unknown Primary and Other Tumours, this is being further investigated. For Other Tumours the high percentage of 9.7% of non-specific of morphology code is mainly noted as a pathology data transfer coding problem for carcinoma in situ of skins, this will be resolved.

Demographics

Ethnicity continues to be problematic for collection in NI as this is not recorded in the main data sources.

Diagnosing Hospital Known

This is a data field that is not routinely collected by the NICR. For many patients their diagnostic pathway can be shared between primary care and secondary care, it can also be shared between multiple hospitals across the same Trust, and in some instances across Trusts. We supplemented this with referral data into the MDT, hence why it is low.

Treatment

As described above the NICR had challenges in gaining treatment data this year. We have previously noted the low capture of surgical treatment for malignant melanoma, and are working to try and improve this. Another issue is the capture of surgery for NMS, which isn’t recorded in our current data feeds. NICR submitted information on the watchful wait/active monitoring treatment pathway, which may not be complete as in NI it is only captured in the first line of treatment data feed and patients come on/off this pathway at various times. Palliative care is also most likely an underestimate as recording is incomplete on the systems that the NICR has access to. We received radiotherapy data too late for submission to the PI’s due to aforementioned upgrades in the radiotherapy system. However, the data now includes health & care number which will facilitate easier linkage to NICR registrations moving forward.

Staging

The NICR has year on year improved the completeness of tumours staged and achieved a level of 84.7% which was well above the UKIACR target of 70%. The NICR registrars actively carry out staging across all tumour sites where appropriate, which in turn has also led to more accurate tumour information such as site and morphology.

Grade

The percentage of cancers with a known grade recorded in 2016 improved to 64.4% This is a great achievement as, like stage, grade is not provided to the Registry as a loadable data field from data feeds but is manually input whilst the tumour registrars are reading pathology reports for tumour staging.

Conclusions

The NICR is pleased that these performance indicators continue to highlight the consistently high quality held within the Registry. In particular, attaining high levels of staging and grade in the absence of automated data feeds has been a great achievement due to the diligence of our Tumour Verification Officers. The absence of screening and treatment data has been noted.

Conclusions

The UKIACR performance indicator data demonstrates the improvements made by each registry over the last year and continues the trend seen in recent years.

Cancer incidence is continuing to increase year on year for the majority of cancer types, in particular increases in incidence in all countries for malignant melanoma, breast in-situ, and squamous cell carcinoma. Those cancers showing decreases in all countries are haematology, cervix and cervix in-situ. DCO rates are below the 2% target for the UK and Ireland overall. Improvements can also be seen in terms of the completeness of grade of differentiation and stage at diagnosis.

The quality and timeliness of data held by cancer registries in the UK and Ireland continues to improve with areas highlighted for action for particular cancer registries to improve data completeness to be in line with other UK and Ireland cancer registries.