United Kingdom and Ireland Association of Cancer Registries (UKIACR)

Performance Indicators 2019 report

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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. This report is primarily based on 2017 registrations. However, there have been delays in registrations from implementation of new systems in Wales and Ireland. Wales reports on 2016 registrations, but unfortunately Ireland has not participated.

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 four UK countries and another based on the population of the four 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 December 2018 allowing the quality assurance team time to run their checks in January 2019. Therefore, the data on 2017 diagnoses used in this report were extracted from an analysis snapshot taken at the beginning of February 2019 (02/02/2019).

We achieved the same overall staging ascertainment result (81.9%) as last year. However, investigations carried out on the data extracted for the report have identified haematology cases where staging had been provided to us that was not recorded on the tumour. A system validation issue (now fixed) was preventing some staging values from being presented to registration teams and a proportion of the staging data was submitted after we had finished processing the registration. Data completeness reports have been modified to ensure we capture these data going forwards. Providers submitting late stage will also be contacted. We are currently processing the missed values; if all the data are valid then it looks as though we should have achieved 82% or possibly higher.

Our DCO rate has risen slightly from 0.5% to 0.6% whilst the proportion of zero day survivors has remained constant at 1.3%. Both are still higher than those reported for Scotland and Northern Ireland, although lower than Wales. From the detailed breakdown CUP cases are the main difference for DCO registrations whilst for zero survivors there are differences in older patients, HPB, Trachea, Bronchus and Lung, CUP and Other invasive cancer cases. We have investigated these differences before and there are no further improvements to be made.

A member of the NCRAS senior team is continuing to work with the screening services to establish routine national exchanges of cervical and bowel screening data. A partial return of cervical screening data was received for the 2016 diagnosed cases we submitted at the end of the year. In November 2017 we added bowel screening categorisations for 2006 to 2015 diagnoses and are carrying out a comparative quality assurance exercise with the BCSP on these cases prior to a further exchange for 2016 diagnoses.

Migration to a single system and the introduction of the Cancer Outcomes and Services Dataset (COSD) in 2013 should be having less of an impact on stability of incidence now that 2013 diagnoses have ceased to contribute to the calculation of the expected incidence. The observed variations in stability of incidence do seem more in line with the other countries. It is interesting to note that the increase in Head and Neck cancer incidence which was only observed in England last year is now evident in all countries as is the significant fall in cervix *in situ* incidence (which we discussed in detail in last year's commentary).

Not achieving 100% microscopic verification for our breast *in situ* cases was frustrating. However, on reviewing the 7 cases in question, we had received information from providers to support these diagnoses.

The SACT dataset was incorporated into routine registration processing for cases diagnosed from April 2017. Therefore, the figure reported here for proportion of cases treated with chemotherapy where the drug name or regimen was known does not represent the full year.

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 (99.3%), tumour (97.4%) and treatment information (89.2%) have been maintained. Delivering this standard year on year is a tremendous achievement.

Commentary for Scotland

This commentary is focused primarily on the Executive Summary table.

Stability

Overall stability for Scotland is -0.8%. One contributing factor to this may be the lack of a radiotherapy data stream, as noted last year. Work is underway as part of the Scottish Cancer Registry and Intelligence Service (SCRIS) to receive a new data feed for radiotherapy data. It is hoped this data should be available by the end of 2019 for data from 1 January 2019 onwards. The increase from last year is likely due to more datasets (Cancer Waiting Times) now being linked to cancer registrations as part of the quality assurance process.

Registry creep

The figure for Scotland (4.0%) is the highest of the four 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. We expect that the renewal of the radiotherapy data feed in 2019, which stopped in April 2016, should reduce registry creep.

Staging

The proportion of staged cancers in Scotland has increased from 67.2% in 2016 to 67.5% in 2017. 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	74.6%	87.0%
Lung	89.8%	92.5%
Breast	84.2%	90.4%
Cervix	95.7%	95.6%
Prostate	83.9%	89.5%

Average of core patient information complete

The figure for Scotland (96.5%) is low because completeness of ethnicity was 72.0% which reduced the average percentage. All other items contributing to this indicator are 100% complete.

Average of core tumour information complete

The figure for Scotland (96.1%) is similar to the UKIACR average of 96.9%.

Diagnosing hospital known

The figure for Scotland (93.0%) is the lowest of the four UKIACR registries that have been reported this year. This will not include primary care locations in Scotland.

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 0.6%).

Zero day survivors

Scotland has the lowest proportion of zero day survivors (0.5% compared with the UKIACR average of 1.0 %).

Microscopically verified

The figure for Scotland is 82.1% compared to the UKIACR average (84.3%). 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 (1.1% 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 (59.0%) than the UKIACR average (61.3%).

Treatment

The figure for Scotland (68.0%) is similar to the figure for last year. Treatment for Teletherapy, Brachytherapy and Watch & Wait / Active Monitoring will also be included next year.

Breast Screening Data

Scotland’s figure of 48.0% of breast cancers detected by screening in the age range 50-64 years is similar to the UKIACR average of 48.2%. It is not clear to what extent this measure reflects uptake of screening or quality of Registry data.

Cervical Screening Data

Scotland’s figure for cervical cancers detected by screening in the age range 25-60 years was 50.4%. This is higher than the previous year (45.3%). Only England and Scotland submitted figures for this measure, so it is difficult to comment further. It is not clear to what extent this measure reflects uptake of screening or quality of Registry data.

Bowel Screening Data

Scotland’s figure of 29.2% of bowel cancers detected by screening in the age range 60-69 years is similar to the figure in 2016. Only Wales and Scotland submitted figures for this measure, so it is difficult to comment further. It is not clear to what extent this measure reflects uptake of screening or quality of Registry data.

Commentary for Wales

Overview

In Wales, the Welsh Cancer Intelligence and Surveillance Unit saw the realisation of the predicted step change in improvements in cancer registration performance indicators for 2016 registrations. This was down to the implementation of the new CATRIN cancer registration system, the use of both the international classification of diseases for oncology (ICDO3) for clinical coding and the TNM version 7 staging classification and securing new electronic data sources.

We expect further gradual improvements year-on-year from now onwards. Wales is now comparable to other UK registries and meets the expected standard for all key performance indicators.

Improvements of particular note include:

- The large increase in the proportion of cases staged to 79.7% in 2016, from 65.1% in 2015.
- The observed variations in stability of incidence seems in line with other countries. There has been a redistribution of the tumour site incidence, with WCISU now using the more appropriate and specific classification ICDO3 used by all the other UK and Ireland registries, allowing greater comparability. For example, we are now able to differentiate between subtypes for haematological cancers increasing our microscopic verification for this tumour site to over 80%.
- By using automated processes, we are now able to record non-melanoma skin cancers for the first time.
- Grade - the completeness of this performance indicator has significantly improved, achieving over 61% in 2016, compared to 40.3% in 2015. We are now achieving one of the highest levels in the UK.
- Treatment data completeness for Wales is, for the first time, well above the national average at 84.8%. The introduction of new data sources such as radiotherapy, cancer waiting time data, and clinical data from MDTs has contributed to this achievement.

- Death Certificate Only (DCO) rates, and the number of zero day survivors for Wales have fallen, and remain within target, although both remain higher than other UK countries.
- The completeness of ethnicity data - although improving slightly each year - still presents a continuing challenge, as this is not routinely documented in source data electronic feeds.

Conclusion

The implementation of the new CATRIN cancer registration system, new data sources and the new clinical coding ICDO3 have brought about the predicted step change in the improvements to cancer registration performance indicators in Wales for 2016 registrations. We expect further gradual improvements year-on-year from now onwards as the registration team consolidates routine use of CATRIN and we address the registration backlog from the implementation period.

The successful implementation of CATRIN is a reflection of the dedication and commitment of WCISUs cancer registration team who have overcome numerous challenges working with a new system, new data sources and a coding system new to them. The implementation was in collaboration with PHE colleagues and we wish to acknowledge and thank those involved in providing expert support and advice over the last eighteen months.

Meanwhile, WCISU will continue to work closely with NHS Wales, clinicians, the Wales Cancer Network, the third Sector and the Welsh Government to improve cancer data in general terms, which will provide benefits for cancer registration and the resulting cancer health intelligence at a population level.

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.

Registry Creep

Registry creep has increased slightly to 2.6%, this is above the UKIACR average of 2.4%. The reasons for this higher number is unknown. Here are some potential reasons as to why it is rising:

- Later collection of non-pathologically verified indolent cancers.
- The removal of the "Non-Registerable Terms" in the UKIACR Cancer Registration Guidelines.
- Normally by the freeze date the NICR will have viewed all the notifications for cancer for the following data collection year for the month of January. Due to time constraints this was not the case this year.

There has been an increasing trend in the overall number of cancers year on year and when examined by tumour site and sex, differing trends have been identified. In 2017 there was a significant increase in thyroid cancer in the 2017 dataset. The Northern Ireland Cancer Network Thyroid Clinical Reference Group confirmed that this is due to better access across the region to ultrasound and is reflective of increased workloads seen within clinics. In 2017 there was also a significant decrease in cervical *carcinoma in situ*, this is also the case across the UK and is due to a combination of reasons to include: changes in triaging patients for cervical biopsy, decreasing participation in cervical screening and due to HPV vaccinated girls now being within the age group of the cervical screening programme.

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 0.3% for the combined group of all registrations.

Zero Day Survivors

At 0.6%, the percentage of zero day survivors for NI was below the UKIACR Country average of 1.0%.

Microscopic Verification

The NICR had a high level of microscopic verification (86.3%). Also, the percentage of non-specific of morphology codes was similar to other jurisdictions.

Demographics

Ethnicity is not collected in Northern Ireland's Health and Social Care system.

Treatment

Northern Ireland continues to find surgery rates for malignant melanoma problematic. This is due to biopsies which are considered to be both diagnostic and treatment not being included within the acceptable OPCS4 codes. While radiotherapy rates were similar to the rest of the UK, the figures represented in this report are slightly under-represented as the North West Cancer Centre opened and had started treating patients. In 2017 the Centre had only just started operation in a phased capacity therefore the numbers of patients missed is low. We expect to include these patients in next year's report.

Watchful wait/active monitoring

In NI Watchful wait/active monitoring it is only captured in the first line of treatment data feed. In practice patients come on/off this pathway at various times, the NICR would question its usefulness. NI's figures were slightly below the rest of the UK.

Palliative Care

Although the figure for the percentage of cancers treated with palliative care in NI (9.9%) was similar to that of England (9.4%), it is most likely an underestimate as recording is incomplete on the systems that the NICR has access to.

Screening

The NICR was unable to supply screening data for breast, cervical and colorectal cancer. This is due to lengthy governance procedures post implementation of GDPR regulations. We expect to include screening next year.

Staging

The NICR has again achieved a high level of staging 85.3% which was well above the UKIACR target of 70%. The NICR registrars actively carry out staging across all tumour sites.

Grade

The percentage of cancers with a known grade recorded in 2017 improved to 65.6% and was above the UKIACR country average of 61.3%.

Conclusions

The NICR is pleased that these performance indicators continue 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 registrars. The PIs provide a welcomed opportunity to monitor our data and as a result drive continued improvement within our Registry.

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/ascertainment is continuing to increase year on year for the majority of cancer types. In particular, increases are observed in all countries for head and neck as well as brain and CNS cancers. Cervix *in situ* decreased significantly across all countries. DCO and zero survivor rates are below the 2% target and the proportion of tumours staged consistently exceeds the 70% target for the UK overall.

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.