United Kingdom and Ireland Association of Cancer Registries (UKIACR)

Performance Indicators

2020 report on 2018 data

Contents

Introduction

In general, all five UK and Ireland cancer registries aim to 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.

However, 2020 has been a year like no other with the global Covid-19 pandemic impacting on the work of the UKIACR and individual registries in several ways. There have been at least two significant impacts on these Performance Indicators

- The publication as a whole was delayed. This report would usually have been published in the summer of 2020, but due to redeployment of analysts and conflicting priorities was only collated in Spring 2021
- The Registry of Ireland has been unable to submit any data to the 2020 report.

Thus this report consists of data from the four UK cancer registries.

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 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 completed their routine processing in February 2020 allowing the quality assurance team time to run their checks in March 2020. Final QA checks were reviewed during COVID-19 ‘lock down’ when remote access to trust systems was not available to registration teams.

The data on 2018 diagnoses used in this report were extracted from an analysis snapshot taken at the beginning of April 2020 (04/04/2020).

Stability of incidence figures for persons (4.1%) and males (6%) have been impacted by the dramatic increase in prostate incidence (19.8%); registration teams having processed 8,000 more prostate cases than expected this year. The ‘Fry/Turnbull’ effect has been coined for the increase, as both men revealed their diagnoses in 2018. There was media interest and a significant increase in awareness. It will be interesting to see whether this results in a decrease in incidence in subsequent years.

The overall increase in female incidence (0.7%) is despite an 11% decrease in the incidence of in situ cervix. This decrease could be consistent with the introduction of the HPV (human papillomavirus) vaccination programme in 2008 but could be confounded by a reduction in women presenting for screening. Further analysis demonstrated that, as expected, there were significant decreases in incidence in the 20-24 and 25-29 age groups. ‘HPV vaccine reducing cancer-causing infections’, a PHE data release for Cervical Cancer Prevention Week (20-26 Jan 2020), reported that cancer-causing HPV16 and 18 infections are now extremely uncommon in young sexually active women in England. In a sample of 584 young women tested in 2018, no HPV16 or 18 infections were detected.

If there is such a dramatic decrease in cervix in situ incidence why isn't this reflected in a fall in invasive cervix incidence (3.3% non-significant increase)? This could be an ongoing consequence of the death of Jade Goody in 2009. Many more women presented for screening that year and every three years that larger cohort will be recalled; 2018 was such a recall year. Age group analysis was consistent with that hypothesis; the increase in incidence being observed in the older age groups, with the 20-24 and 25-29 age groups demonstrating a decrease.

The most significant increase in incidence for females, aside from the continuing increase in melanoma skin cancer (8.2%), was in in situ breast cancer (7.3%) with a smaller increase in invasive disease (3.9%). In May 2018, a national breast screening incident was announced in response to a system failure of the NHS Breast Screening Programme to offer over 120,000 women their final screen in the 36 months before their 71st birthday. In response to this incident thousands of women were invited for screening who would not normally have been screened in this period. An increase in breast incidence (invasive and in situ) was a likely outcome of this activity. Looking at age breakdowns we could see that the significant increase in incidence was in the 70-79 age group (invasive 15% and in situ 30%).

An important change was made in the way that NCRAS recorded haematological transformations; previously, transformations were recorded as a second tumour. From 2018 diagnoses a transformation event was added to the original record. Consequently, a fall in incidence was expected and a 20% fall in AML incidence was predicted. A decrease in incidence was observed for males (-2.9%), females (-4.2%) and persons (-3.5%). The fall in AML incidence was consistent with predictions.

Registry creep was similar this year (1.2%) to last (1.4%). If this were due to incomplete processing, rather than late notification, you would expect the number of cases to increase following the processing of the first quarter of 2019. Following the processing of January to March 2019 diagnoses, the registry creep was calculated at 0.3%.

There was a slight fall in the overall staging ascertainment result from 81.9% last year to 81.3% this; the reduction was across all sites. A stage investigation tool has been produced to enable offices to explore stage performance by tumour site and data provider.

I'm pleased to report that our DCO rate has remained at 0.6% following a rise of 0.1% last year; the proportion of zero-day survivors has fallen slightly from 1.3% to 1.2%.

Throughout the year collaborative work continued with the screening services to establish routine national exchanges of cervical and bowel screening data. Our screening data for breast and cervical diagnoses, current and previous years, were similar to those reported last year. Bowel screening categorisations for 2017 diagnoses were received prior to the PI snapshot being taken but unfortunately, technical changes required to load the data could not be implemented in time for the extract.

Overall, high values for staging (81.3%), average completeness of core patient (99.2%), tumour (97.5%) and treatment information (88.8%) are testimony to the skill and dedication of our registration teams. Delivering this standard next year following COVID-19 disruptions will be a significant challenge.

Technical Note:

Users of National Statistics publication '*Cancer registration statistics: England 2018 final release*' [https://www.gov.uk/government/statistics/cancer-registration-statistics-england-2018-final-release] may notice that there are differences between the 'All Registrations' figures in that publication and those reported here; these are largely due to the way the two publications handle non-malignant neoplasms.

UKIACR PI specification for the 'Other Tumours Group' **includes**: D00-**D04**, D07-D09, **D29.2**, D32-D33, D35.2, D35.3, D35.4, D37-D48
National Statistics specification **excludes**: D04, D10 to D31, D34 to D35.1 and D35.5 to D36

In the PIs, NCRAS reported 210 more cases for 2018 incidence. D04 registrations accounted for 174 cases, there were 12 registrations for D29.2 and the remaining 24 cases were found to be errant D codes that should have been excluded from the indicators. The PI queries have been modified to exclude these errant codes.

Commentary for Scotland

This commentary is focused primarily on the Executive Summary table.

Stability
Overall stability for Scotland is +4.6%. Public Health Scotland undertook a linkage exercise with the West of Scotland Cancer Network linking **myelodysplastic syndromes,** myeloproliferative disorders, **lymphoproliferative disorders** and acute leukaemia to the cancer registry. This has increased the data completeness compared to previous year's incidence of unknown registrations.

Registry creep
The figure for Scotland is 1.9%. Registry Creep has improved, having reduced from 4% to 1.9% this is the lowest for Scotland for many years. This is mainly due to the implementation of an additional deadline for staff to work to. Where Q1 of the next reporting year is included within the reporting year. This ensured that any late 2018 registrations which had been assigned a provisional incidence date of Q1 2019 were reviewed and completed. We now received radiotherapy data directly from two Scottish centres.

Staging
The proportion of staged cancers in Scotland was 67.6% in 2018 compared 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	73.5%	87.2%
Lung	93.2%	93.1%
Breast	87.1%	91.3%
Cervix	94.8%	90.0%
Prostate	83.4%	89.6%

For melanoma there is a significant difference between Scotland (37.9%) and the other registries. Clinical TNM is assigned to the record before surgery. In most circumstances due to the clinical pathway nodes are not assesses at the clinic before surgery. After surgery and melanoma confirmed nodes are then assessed. We would not apply clinical stage after surgery and we do not assume N0, M0 if less than or equal to 1mm and T1a or T1b. These are assigned NX, MX. this then results in our overall stage being unassigned.

Average of core patient information complete
The figure for Scotland (96.3%) is low because completeness of ethnicity was 70.4% which reduced the average percentage.

Work is underway to explore how we can improve the completeness of ethnicity.

Average of core tumour information complete
The figure for Scotland (96.4%) is similar to the UKIACR average of 96.9%.

Diagnosing hospital known
The figure for Scotland is 94.1%. This will not include primary care, breast screening or private hospital 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 82.4% 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 (0.9% compared with the UKIACR average of 1.1%).

Grade [of differentiation]
The proportion of cancers recorded with a known grade of differentiation is similar in Scotland (59.7%) to the UKIACR average (60.9%).

Treatment
The figure for Scotland (85.6%). This is higher than previous years due to Watch & Wait and Palliative Surgery now being included in this calculation. Treatment figures for Teletherapy, Brachytherapy and Watch & Wait / Active Monitoring have been presented separately this year for the first time.

Breast Screening Data
Scotland's figure of 50.1% of breast cancers detected by screening in the age range 50-64 years in 2017 is similar to the UKIACR average of 51.3%. It is not clear to what extent this measure reflects uptake of screening or quality of Registry data.

Cervical Screening Data
Scotland's percentage of cervical cancers detected by screening in the age range 25-60 years was 49.3% in 2017, compared with 50.4% in 2016. 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 29.4% of bowel cancers detected by screening in the age range 60-69 years in 2017 is similar to the figure in 2016. Only Scotland and Wales 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

Stability

Overall stability for Wales for the 2018 data is +4.1% (statistically significant), compared with -0.3% for 2016 data in previous PIs, and the UKIACR 2018 country average of 3.8%.

As for other registries, the increase is in part due to prostate and bladder cancer, possibly as a result of the effect of Fry and Turnbull awareness - bladder cancer may be an incidental finding from prostate cancer diagnosis.

Another contributing factor in the case of WCISU, is the improved remote access to NHS Wales information systems.

Haematology remains an area for ascertainment improvement – at present there is limited information on haematological cancers available from the Welsh MDT electronic patient system Canisc – this should improve with a new clinical information system currently under development.

Registry creep

At 0.32% for 2018, registry creep has improved considerably from the previous creep figure for Wales for 2016 data which was 1.6%. This is largely down to new practices and some automation, new data sources and increased resources and training. The UKIACR country average remains at 1.6%.

Staging

The proportion of verified staged cancers (excluding NMSC) in Wales was 79.6% in 2018, which is higher than the UKIACR country average of 77.2%. In Wales, the proportion was 79.7% in 2016. For 2018 registrations, WCISU moved to staging using the TNM 8th edition. Despite the transition, the existing high overall staging completeness for the main sites were maintained.

The exception is breast cancer. In Wales the 2018 stage completeness was 82.0% compared to the UK average of 91.3%. In 2016 data, the Wales breast stage completeness was also comparatively low at 85.7%. Preliminary investigation suggests that the staging completeness is lower for cases resident in some but not all of the seven health boards in Wales. Further investigation is continuing to ascertain whether this is a data issue or a clinical issue.

Verified staging completeness for main cancer sites

Cancer site	Wales 2018	UKIACR 2018 average
Lower GI	92.0%	87.2%
Upper GI	82.8%	79.0%
Lung	92.2%	93.1%
Breast	82.0%	91.3%
Cervix	96.3%	90.0%
Prostate	93.7%	89.6%
Bladder	82.9%	83.2%

Kidney	79.1%	83.1%
Head and neck	87.2%	87.4%
Melanoma of skin	90.9%	88.3%

Average of core patient information complete

The completeness for Wales very high or 100% complete for most variables, except for ethnicity. This is due to an ongoing problem with poor completion and accuracy in the underlying NHS Wales source datasets.

Work is underway to explore how we can improve the completeness of ethnicity in the registry database, and also when analysing the data to produce official statistics.

Average of core tumour information complete

Most variables are almost 100% complete, apart from 'type of growth' which is slightly lower. The overall completion is similar to the UKIACR population average.

Diagnosing hospital known

The completion of this variable is very high and very similar to the UKIACR average.

DCO rates

Scotland has the lowest proportion of death certificate only (DCO) cases of 0.2% compared with the UKIACR average of 0.6%. However, the overall proportion tends to be the highest in Wales at 1.2% for 2018 data, although this has reduced from 1.3% in 2016 data, it remains double the UKIACR average.

Despite significant improvements, including for haematology cancers in particular, for example, several cancer sites continue to contribute to the overall 1.22% DCO proportion in Wales in the 2018 data (see table X). However, notably, the DCO proportion for people with cancer 80 years and over in the Wales 2018 data is 4.3% compared to the UK average of 1.9%, a ratio of 2.3.

The 2018 DCO proportion was lower in Wales than the UK average for head and neck, cervical and brain/CNS cancers.

The DCO proportion will be investigated further to establish to what extent it is due to data and ascertainment issue, varying across different cancer types, or whether there is, in part, a 'real' effect, particularly related to older people who develop cancer.

Cancer sites where ratio of DCO% in Wales to UK average is >1.5 for 2018 data

		% DCO 2018		
		Wales	UK average	Ratio Wales:UK average
	All invasive xnmsc	1.22%	0.6%	2.0

	Haematology	2.12%	0.7%	3.0
	Lower GI	0.92%	0.5%	1.8
	Upper GI	1.52%	0.5%	3.0
	HPB	1.68%	1.0%	1.7
	Breast	0.68%	0.3%	2.3
	Other female genitals	1.11%	0.6%	1.9
	Prostate	0.87%	0.4%	2.2
	Bladder	2.41%	0.7%	3.4
	Thyroid & other endocrine glands	0.63%	0.4%	1.6
	CUP	7.65%	4.2%	1.8

Zero day survivors

Wales was 1.9% zero day survivors in 2018 data, compared with 1.6% in 2016 data. The UK average was 1.0% for 2018.

Microscopically verified

The figure for Wales was 84.1%, compared to 83.4% in 2016 Wales data, and the 2018 UK average of 84.3%.

Non-specific [morphology] codes

Wales has improved with a low proportion of non-specific morphology codes recorded of 0.73% compared to 1.5% in 2016 Wales data, and the 2018 UK average of 1.1%.

Grade [of differentiation]

The proportion of cancers recorded with a known grade of differentiation for Wales was 60.9% in 2018 data, the same as the UK average.

Treatment

The treatment data was 82.5% complete in Wales for the 2018 data, compared to the UK average of 85.6%. However, the proportion for Wales in 2016 data was 84.8%.

Breast Screening Data

In Wales, the 2018 cancer registry data included 55.1% of breast cancer cases detected by screening in the age range 50-64 years in 2017. This is similar to the UKIACR country average of 51.3%. It is not clear to what extent this measure reflects uptake of screening or quality of registry data.

Cervical Screening Data

Only England and Scotland submitted figures for this measure. Although the source data is available in Wales, it does not currently map to the registration system. However, the process of importing and using the data within cancer registration is now already occurring, but after the PIs were submitted.

Bowel Screening Data

The Wales registry had 27.5% of bowel cancers detected by screening in the age range 60-69 years in 2017, compared to 28.4% in 2016 data. Only Scotland (29.4%) and Wales submitted figures for this measure, and both have similar proportions. Again, it is not clear to what extent this measure reflects uptake of screening or quality of cancer registration data.

Commentary for Northern Ireland

The N. Ireland Cancer Registry (NICR) is a part of Queen's University Belfast and 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.

Due to the Covid-19 pandemic, staff have been working remotely from the beginning of March 2020 with access to a reduced anonymised dataset. Therefore, the NICR has not been able to provide data for all the performance indicators. The dataset used for 2018 performance indicators was extracted at the end of January 2020, whereas in previous years the datasets were not frozen until the end of February or later.

There has been a steady increase, year on year of the number of registered invasive cancers excluding non-melanoma skin cancers (9,499 registered in 2015, 9,897 registered in 2019). This increase is to be expected within an aging population.

There was a significant increase in the number of prostate cancers registered in 2018, this is most likely due to the "Fry and Turnball effect"[1] and also the free PSA testing which were offered to men over the age of 40 years by Randox Health Clinics throughout November 2018.

There was a large increase in the number of non-melanoma skin cancer diagnosed for both males and females in 2018. This is most likely due to increased patient awareness and the identification of patients diagnosed in private hospitals.

There was a significant drop in the number of kidney cancers diagnosed in males in 2018. The 2017 figures were particularly high compared to previous years, which makes the drop in 2018 appear larger. However, the NICR may be missing clinically verified low stage kidney cancers due to a regional change in practice from a diagnosis via CT scan and biopsy to diagnosis via CT scan (without a biopsy) with subsequent treatment via Radio-frequency ablation (RFA). These clinically radiologically verified cancers may have been missed as the NICR does not currently have routine access to radiological data and RFA. Further evidence that these radiologically verified cancers may be missing can be found via the data on microscopic verification of kidney cancers which has dropped from 79.9% (2016) 76.7% (2017) down to 69.7% in 2018. This is a reflection of the lower number of biopsies now being performed.

The number of registrations for breast cancer have steadily increasing over the years with a significant increase this year for in-situ breast possibly due to increased screening both by Action Cancer and the Breast Screening Service.

Registry creep: This has increased from 2.59% in 2019 to 2.82% for 2020. It is also higher than the UK country average of 2.0%. However, as the DCO rate is low, it is unlikely that the increase in creep is due to late registration but is simply due to yearly variation.

DCO rate: The NICR continues to achieve a DCO rate well below the 2% target, with a level of 0.26% for invasive cancer excluding NMSC and 0.16% for all registrations. The DCO rate is low across each of the tumour groups, except for cancers with an unknown primary where it is 2.33.%. Higher levels are not unexpected in this tumour

group as many patients have a short survival which may mean that it was not possible to fully investigate to provide an accurate diagnosis prior to death.

Zero day survivors: At 0.47%, the percentage of zero day survivors for NI was below the UKIACR Country average of 1.1%. Zero survival was below 1% for all cancer sites except for patients over 80 years (1.31%), cancer with unknown primaries (3.72%) and other invasive cancers (2.71%).

Microscopic verification: The percentage of microscopically verified cancer cases remained high at 85.66%. This year's figure is significantly lower than the 90.87% from the previous year which is undoubtedly due to the data being extract a month earlier than usual.

Demographics: Collection of data pertaining to ethnicity remains difficult for the NICR as this information is not recorded within the primary sources of data.

Diagnosing Hospital Known: The NICR was unable to provide information on the diagnosing hospital this year as we were unable to access the datasets remotely.

Treatment and Screening: Unfortunately, the NICR was unable to provide information on treatments or screening this year as we were unable to access the datasets remotely.

Staging: The NICR has achieved a level of 80.04% which was well above the UKIACR target of 70%, however it is below the 84.7% achieved in 2016 and the 85.3% achieved in 2017. The data used to compile this year's PI report were extracted in January 2020 and although further staging had been carried out between February and May 2020, we were unable able to access this data remotely for inclusion in the report.

Grade: The percentage of cancers diagnosed in 2018 with a known grade was 63%, this is a drop from last year (65.6%). However, like the staging, this is most likely due to the dataset being extracted at end of January. Grade and stage are not provided to the Registry as a loadable data fields from the data feeds and are manually recorded by the tumour verification officers whilst reading pathology reports. Despite this drop in percentage, the NICR is still above the UKIACR country average of 60.8%.

Conclusions

The NICR is pleased that these performance indicators continue highlight the consistently high quality held within the Registry. The PIs provide a welcomed opportunity to monitor our data, and as a result drive continued improvement within our Registry

[1] https://www.bbc.co.uk/news/health-45795337

Conclusions

Covid-19 impacted the registries in the UK and Ireland in many ways this year, with Ireland unable to provide any data for this report, and submissions from England, Northern Ireland and Wales all delayed. However, the UKIACR performance indicator data continues to demonstrate the improvements made by each registry over the last year and continues the trend seen in recent years.

[The full impact of Covid-19 on cancer registration data is not yet fully seen in these Performance Indicators, as 2018 data was mostly finished in the majority of countries before the pandemic impacted registration. The 2019 data will need careful review, as registries have been affected in a variety of ways, including being unable to access sources remotely to check for/access screening, staging and treatment information.]

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 prostate cancer, largely driven by the 'Fry/Turnbull' effect, with an overall increase of 17%. Cervix in situ decreased significantly across all countries (16% decrease).

DCO and zero survivor rates are below the 2% target and the proportion of tumours staged exceeds the 70% target for the UK overall, although Scotland continues to have slightly lower completeness at 68%.

The quality and timeliness of data held by cancer registries in the UK and Ireland continues to improve, and the Performance Indicators remain an important part of driving this improvement by reviewing data quality and providing comparative benchmarks.