



# **UNITED KINGDOM AND IRELAND ASSOCIATION OF CANCER REGISTRIES ANNUAL PERFORMANCE INDICATORS FOR DATA PUBLISHED IN 2015**

**REPORT PREPARED FOR UNITED KINGDOM AND  
IRELAND ASSOCIATION OF CANCER REGISTRIES BY  
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## Contents

INTRODUCTION .....	3
COMMENTARY FOR REGISTRATIONS AND TIMELINESS REPORTED .....	5
COMMENTARY FOR ASCERTAINMENT .....	6
Stability of incidence by cancer site .....	6
Death Certificate Only (DCO) Rates .....	9
Microscopic Verification .....	11
Mortality:Incidence (M:I) Ratios .....	12
COMMENTARY FOR COMPLETENESS OF THE DATASET .....	14
Demographics and Diagnostic Details .....	14
Screening Information .....	15
Site Specific Information for Breast Cancer .....	16
Detailed Stage Information .....	16
Conclusions .....	19

## INTRODUCTION

National population based cancer registries in the UK and Ireland, where possible, collect a range of data quality indicators across all cancers excluding non-melanoma skin cancer (NMSC). These performance indicators (PI) include the number of annual cancer registrations, the percentage of registrations reported via Death Certificate Only channels (DCOs), the percentage of registrations with microscopic verification and staging information, the percentage of registrations with demographic and diagnostic information, and the mortality:incidence (M:I) ratio. These metrics provide a way of quantifying areas where data are more complete, whilst also comparing both the similarities and differences between each country's dataset. This process provides a mechanism to peer review performance each year.

By collating this data, we can also examine the way that information is processed and how the data sources available help identify and facilitate improvements to the cancer registration process. We hope this will in turn generate more efficient practices and better quality data. Improvements can be seen in this year's performance indicators compared to last year but quality improvement is a continuous process and this is an ongoing programme of work.

The national cancer registry bodies involved are the English National Cancer Registration Service (NCRS), the Scottish Cancer Registry (SCR), the Welsh Cancer Intelligence and Surveillance Unit (WCISU), the Northern Ireland Cancer Registry (NICR) and the National Cancer Registry Ireland (NCRI) and this report concerns PI data for all cancers (excluding NMSC) diagnosed in 2013, as registered by 15 February 2015 and published in 2015.<sup>1</sup>

Cancer registration data in England is now available from one consolidated source, the National Cancer Registration Service based on the ENCORE system (the English National Cancer Online Registration Environment), whereas prior to the 2012 registration year data was provided from eight regional cancer registries across England on separate systems. This migration onto ENCORE better enabled the service to reduce duplication and maximise the use of electronically available data sources and a high tech registration system to collect and provide high quality cancer registration data. As with previous years, there is one single national cancer registry for all the remaining countries in the UK and in Ireland providing consolidated cancer registration information. In order to ascertain the overall performance of the UKIACR across the different PI metrics, non-weighted averages were calculated for all measures (except staging data which instead used weighted averages). This means that the averages haven't accounted for the different population sizes in each country.

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<sup>1</sup> Data from the NCRI which covers the Republic of Ireland is for patients diagnosed in 2012 and this is the case for all sections, except for the data found in the "commentary for registrations and timeliness reported" section

It is important to remember that each of the national cancer registries within the UKIACR are served by different population sizes and each registry will process a different number of annual registrations and will be involved with a different network of data providers. Caution is therefore required when making performance comparisons between countries. For example, large percentage changes outside England may represent change in a small number of people whereas in England a small percentage change may impact a large number of people.

Strong areas from the 2013 data include improved staging rates within the cancer registries, which were highest in Northern Ireland across all invasive tumours (excluding NMSC, which although common, they rarely cause mortality and are not collected routinely by all registries) and saw all countries within the UK and Ireland achieving more than 60%, except for Scotland which had a staging completeness across the group 'all cancers' of 42%. However, staging data in Scotland are also collected separately for selected cancers through cancer audits, and the range of cancers for which staging information is collected by the cancer registry is increasing over time, following the development of cancer Quality Performance Indicator (QPI) data sets in Scotland. Further staging data is also separately available in national audit data sets and in the MDT electronic cancer clinical record system in Wales.

Areas which need improvement include Death Certificate Only (DCO) rates in England, where levels are still above the 2% target for both males and females (though there had been a decline from 2012 to 2013 in both sexes). Haematological staging data is low across all registries. The UKIACR non-weighted average is 22% and Scotland, Wales, and Northern Ireland fall below this level. Improvement is also required for sarcoma staging data which has a non-weighted average stage completeness of 31%. The following sections will discuss performance across the specific indicators. The data described below is only a snapshot and measurement of these indicators should not distort priorities where that is not desirable. A significant change in PI data between years is identified by the presence of an "\*" after the figure.

Please note that the data from the NCRI which covers the Republic of Ireland is for patients diagnosed in 2012 and this is the case for all sections, except for the data found in the "commentary for registrations and timeliness reported" section.

The data from this report is available as a supplementary appendix.

## COMMENTARY FOR REGISTRATIONS AND TIMELINESS REPORTED

The measures in this section can only act as indicators and relate to data quality. These should not be used to draw conclusions about recent epidemiological trends in incidence as numbers are likely to change because of late registrations and other factors.

The combined number of registrations in England, Wales, Scotland, Northern Ireland and Ireland increased in 2013 compared to previous years (2013 registrations were 1.3% higher than in 2012) and total registrations continue to increase. The largest increase in registrations was in Wales (4.85%) followed by England (1.58%), however there was a decrease in the number of registrations between 2012 and 2013 in the remaining countries (Scotland: -0.60%, Ireland: -1.60%; Northern Ireland: -1.32%). The number of finalised cases in each registry was generally above the 2010 to 2012 average and it was highest in Wales (104.8% of the 2010 to 2012 average), followed by England (103.5%), Northern Ireland (102.3%) and Scotland (100.3%). It was slightly below 100% in Ireland (99.4%).

Both NICR and NCRS commented that the rise in the number of cases is probably a real effect, driven by the aging population. The observed rise in cases in England is typical compared to previous years, and is not the greatest rise seen across the UKIACR. NCRS suggested that part of this rise, particularly the increase in the number of clinically diagnosed cancer registrations may be due to better access to data. There have been improvements in access to data in 2013, including the introduction of the Cancer Outcomes and Services Dataset feeds and increased remote access to Trust systems.

### Cancer Registrations: 2012 - 2013

#### Annual Number of Cancer Registrations (Excluding NMSC), UK & Ireland

Registry	2012	2013	Change in Registrations (%)
England	286,774	291,299	1.6%
Scotland	31,126	30,939	-0.6%
Wales	18,329	19,218	4.9%
Northern Ireland	9,023	8,904	-1.3%
Ireland	20,402	20,076	-1.6%
<b>UKIACR Total</b>	<b>365,654</b>	<b>370,436</b>	<b>1.3%</b>

## COMMENTARY FOR ASCERTAINMENT

### Stability of incidence by cancer site

Variations in the percentage change of registrations across the UK and Ireland may reflect changes in the efficiency and accuracy of data collection by registries, random variation, or genuine differences in incidence trends.

#### Prostate cancer

In England, Wales and Scotland, there was a significant increase in the number of cases of prostate cancer in 2013 compared to the average 2010 to 2012 (9.1%\*, 7.1%\* and 4.5%\*, respectively). These increases are all above the non-weighted UKIACR average (+4.3%) and the change is primarily due to a rise in the actual number of clinically diagnosed cases which are then recorded by the registry (the “Commentary for registrations and timeliness reported” section).

#### Skin melanoma

There was an increase in incidence of melanoma of the skin for males in England (10.1%\*), Scotland (6.2%), Ireland (6.7%) and most dramatically in Northern Ireland (28.5%\*). For females, increases have been reported in England (8.5%\*), Wales (0.9%) and Northern Ireland (16.1%). This PI measure for melanoma of the skin has been rising for several years and this is believed to be a real increase as it has been reported to some extent in all areas.

NICR suggest that the pronounced rise found in males in Northern Ireland is also a genuine increase, as each case was histologically verified and further looked at by NICR tumour verification staff for staging purposes.

In England, it is thought that there may be a small effect from underreporting in some regions in 2012 during migration to a single cancer registry system that may be causing the 2013 figures to appear as a larger increase.

#### Colorectal cancer

The number of colorectal registrations decreased in England (-2.9%\* for males and -2.3%\* in females), Scotland (-4.7% in males and -4.8% in females), Wales (-1.8% in males and -5.7% in females) and Northern Ireland males (-3.5%). Conversely, the number of colorectal registrations increased in both Ireland (8.3%\* in males, 1.6% in females) and Northern Ireland for females only (4.4%). In Ireland, the Bowel Screening Programme was rolled out in 2012 which could account for the increase in the detection of colorectal cancers, whereas it is more established in other areas of the UK but not yet established in the Republic of Ireland.

## Breast cancer

There has been an increase in the number of registrations for female breast cancer in situ in England (23.8%\*), Wales (25.1%\*), Northern Ireland (8.1%) and Ireland (6.0%). The NCRS and WCISU commented that there was a change in registration practice in 2012, where it was agreed that if an in-situ pathology report was received prior to an invasive one and there was no clear evidence that invasion was suspected initially then two registrations should be made, of both the in-situ breast cancer and the invasive breast cancer. Previously, it was possible that only an invasive tumour would have been registered. This has created an artificial rise in the number of in-situ breast cancers.

However, there was a significant decrease for female breast cancer in situ in Scotland (-16.8%\*) and the SCR have stated that this decline is difficult to interpret in the context of the breast screening programme. There have been slight decreases in uptake of breast screening in Scotland in recent years, but probably of too small a magnitude to account for the decrease in carcinoma in situ of the breast. Other contributory factors may be an unusually high peak in 2011 (also evident from breast screening data, collected independently), and the introduction of new UK guidelines for registering multiple primary breast cancers for patients diagnosed from 1/1/2012 onwards.

There has been an increase in the number of registrations of invasive female breast cancer in Wales (11.9%\*), England (5.3%\*), Ireland (3.0%), Scotland (2.1%) and Northern Ireland (1.6%). The WCISU believe that this is a real increase, as the trend appears in all countries within the UK and Ireland. The WCISU also commented that the specific trend in Wales is a result of a large decrease in female breast cancer incidence in 2012 followed by a large increase in 2013.

## Cervical cancer

There has been a rise in the number of cervical cancers, both invasive and in-situ, in England (5.9%\* and 6.8%\*, respectively) and Wales (2.5% and 11.7%\*, respectively). The NCRS commented that the noticeable drop of 4% in both invasive and in situ cervical cancer in 2012 was likely to be a result of shortfalls in data exchange with the cervical screening Quality Assurance Reference Centres in certain geographical areas of England and that the 2013 rise is probably due to improved data quality and access. WCISU also commented that from 2012 onwards information from the colposcopy service was sent through and as a result, registrations increased for cervix in situ.

Northern Ireland has seen a rise in invasive cervical cancer (7.2%) and a decline of 14.9%\* for in situ cervical cancer. The NICR commented that the cervix in situ rates have been falling over the past 4 years. All remaining countries have found a decrease for both invasive and in situ cervical cancers (Scotland: -2.7% and -11.5%\*, respectively; Ireland: -15.0%\* and -1.4%, respectively; Northern Ireland: -14.9%\* for in situ cervical cancer). The SCR noted that the decrease in Scotland

for cervix in situ is similar to that in Northern Ireland. The SCR also stated that the decrease in cervix in situ is difficult to interpret in the context of a cervical screening programme, but that there have been slight decreases in uptake of cervical screening in Scotland over the last decade, which may account for this decrease. It is probably too early for the decrease in cervix in situ disease to reflect the impact of the HPV vaccine. The NCRI commented that the National Cervical Screening Programme in Ireland is now well established and a decrease in the number of invasive cervix diagnoses is following expectations and decreasing.

### Lung cancer

There were statistically significant increases in the number of female lung cancers in Northern Ireland (14.0%\*), Ireland (11.7%\*) and England (3.0%\*) with a small non-significant increase in Scotland and small non-statistical decrease in Wales. The NCRS stated that the increase is part of an established trend of increasing rates of female lung cancer. NICR commented that incidence rates of lung cancer in females in Northern Ireland have been increasing and that people who eventually come to NICR as a DCO case (often elderly females) are being identified more efficiently via CaPPs (regional MDT database). The NCRI also address this trend stating that in the period 1994 to 2012 there has been a significant increase of over 2% per annum in the rate of incidence of lung cancer in females. Females in Ireland are ranked amongst the highest in Europe in terms of both the incidence and the mortality of lung cancer.

Whilst the increase in lung cancer registrations in Wales was non-significant, there is an established epidemiological trend for females in Wales in which lung cancer incidence is increasing. The female lung cancer incidence rate in 2013 is 28% higher than in 2003.

### Haematological Malignancies

Haematological cancers have seen an increase in the number of registrations in Wales (males: 14.9%\*, females: 14.6%\*) and England (males: 5.6%\*, females: 3.0%\*). The NCRS have stated that the observed increase in haematological cancers is in part due to the aging population. Leukaemia and NHL are more common in the elderly, and a large percentage of this increase reflects the changing demographics of England. The NCRS comment that the increase in haematological cancers is not consistent across England and has not been seen in all parts of the UK. This suggests that the change is driven at least in part by improving data quality and increasing standardisation of English registration practice. The WCISU also state that the Welsh increase is primarily due to data being received from their data sources in ICD10 version 4 with unspecific morphologies. As a result they are unable to differentiate between subtypes and therefore unable to identify / remove tumours that should now be considered as a single registration by European Network of Cancer Registries (ENCR) rules.

## All Cancers Excluding Non-Melanoma Skin Cancer (C00-97 Excl. C44): 2013 (UK) & 2012 (Ireland)

Percentage Change (%) in Registrations Compared to the 2012-2010 average for the UK and the 2011-2009 average in Ireland, by sex

Cancer Site	UKIACR Average	England NCRS	Scotland SCR	Wales WCISU	Northern Ireland NICR	Ireland NCRI
<b>Lung</b>						
Male	1.0	-0.4	-2.3	2.3	3.4	2.0
Female	5.7	<b>3.0*</b>	0.6	-0.9	<b>14.0*</b>	<b>11.7*</b>
<b>Melanoma of skin</b>						
Male	9.5	<b>10.1*</b>	6.2	-4.2	<b>28.5*</b>	6.7
Female	3.5	<b>8.5*</b>	-6.4	0.9	16.1	-1.4
<b>Colorectal</b>						
Male	-0.9	<b>-2.9*</b>	-4.7	-1.8	-3.5	<b>8.3*</b>
Female	-1.4	<b>-2.3*</b>	-4.8	-5.7	4.4	1.6
<b>Prostate</b>						
Male	4.3	<b>9.1*</b>	<b>4.5*</b>	<b>7.1*</b>	-0.3	1.2
<b>Bladder</b>						
Male	2.9	-1.6	-5.8	11.4	13.8	-3.2
Female	2.4	-4.4	0.4	8.2	2.9	5.1
<b>Haematology</b>						
Male	2.7	<b>5.6*</b>	-4.3	<b>14.9*</b>	-2.0	-0.7
Female	-0.9	<b>3.0*</b>	<b>-8.1*</b>	<b>14.6*</b>	-9.3	-4.6
<b>Breast Invasive</b>						
Female	4.8	<b>5.3*</b>	2.1	<b>11.9*</b>	1.6	3.0
<b>Breast In Situ</b>						
Female	9.2	<b>23.8*</b>	<b>-16.8*</b>	<b>25.1*</b>	8.1	6.0
<b>Cervix Invasive</b>						
Female	-0.4	<b>5.9*</b>	-2.7	2.5	7.2	<b>-15.0*</b>
<b>Cervix In Situ</b>						
Female	-1.9	<b>6.8*</b>	<b>-11.5*</b>	<b>11.7*</b>	<b>-14.9*</b>	-1.4
<b>All Cancers excl. NMSC</b>						
Male	2.6	<b>3.9*</b>	0.5	<b>4.2*</b>	1.6	<b>2.9*</b>
Female	3.0	<b>3.1*</b>	0.1	<b>5.4*</b>	3.0	<b>3.4*</b>

UKIACR averages were calculated using data from all countries in the table and are not weighted

### Death Certificate Only (DCO) Rates

The overall 2% target for (DCO) rates is met for the majority of cancer sites in the UK and Ireland. Northern Ireland are consistently below the 2% target across numerous sites including lung, invasive breast, invasive cervix, melanoma of skin, colorectal, bladder and prostate cancer. There had been an increase in DCO rates for females over 75 years old in 2013 and the NICR clarified that this was due to an additional 16 women all aged over 75 years. The NCRS have not met this

overall 2% target across the different cancer sites and the figures are particularly high for cases 75 years old or older. Although not as high as NCRS, WCISU also has DCO rates above 2% for cases 75 years old and older, and these are above the non-weighted UKIACR average (Wales: males 2.4%; females 3.8%). DCO rates for males aged 75 and over are also above 2% for NCRI.

The NCRS have noted that although their DCO rates did not meet the overall 2% target, they have fallen for all cancer sites in England in 2013 compared to 2012. (It was accepted as a risk by NCRS that the effort required to achieve migration and the focus on staging data would mean that there was less time to complete full follow-up of DCO cases and thus there would be an increase in DCO rates for 2012.). Although the overall DCO rate is below 2% for Wales and has reduced compared to previous years, it remains relatively high compared to Scotland, Northern Ireland and Ireland. And in Wales, even though they are below 2%, DCO rates for lung, colorectal and bladder cancer cases are still relatively high compared to the same countries.

### Various Cancer Sites: 2013 (UK) & 2012 (Ireland) Death Certificate Only (DCO) Registrations (%), Persons

Cancer Site	UKIACR Average	England NCRS	Scotland SCR	Wales WCISU	Northern Ireland NICR	Ireland NCRI
Lung	1.4	2.9	0.2	1.9	0.6	1.5
Breast Invasive	0.3	0.7	0.1	0.6	0.2	0.1
Cervix Invasive	0.2	0.6	0.0	0.0	0.0	0.3
Melanoma of skin	0.1	0.2	0.0	0.1	0.0	0.0
Colorectal	1.1	1.9	0.1	1.7	0.9	0.8
Prostate	0.6	1.5	0.1	0.6	0.2	0.5
Bladder	1.1	2.4	0.1	1.8	0.5	0.7
Haematology	1.2	2.8	0.2	1.3	1.3	0.3
Ill-defined sites	5.9	13.4	2.3	7.7	2.6	3.7
All Cancers excl. NMSC Male	1.0	2.2	0.2	1.3	0.5	0.8
All Cancers excl. NMSC Female	1.1	2.4	0.2	1.5	0.8	0.7
All Cancers excl. NMSC Male<75	0.4	1.0	0.1	0.6	0.1	0.2
All Cancers excl. NMSC Male>=75	2.3	5.6	0.3	2.4	1.1	2.3
All Cancers excl. NMSC Female<75	0.3	0.7	0.1	0.3	0.2	0.2
All Cancers excl. NMSC Female>=75	3.0	6.9	0.5	3.8	2.0	2.0

UKIACR averages were calculated using data from all countries in the table and are not weighted

## Microscopic Verification

Despite small improvements in some female cancer types compared to last year, microscopic verification figures in Wales are below the non-weighted UKIACR average for the majority of cancer types. WCISU fares poorly with this indicator each year as the current primary data source used is administrative data for hospital admissions (PEDW – Patient Episode Database Wales). The 2014 cancer registrations currently being processed by WCISU now use the national cancer MDTs electronic patient record system as the primary data source with several other sources supplementing that. This new process should greatly improve microscopic verification. Currently, due to the introduction of ICD10 version 4, WCISU now receives the majority of haematology data with an unknown morphology and usually an unknown basis of diagnosis. The WCISU sets the morphology as 8000/3 to distinguish these unknown cases. This will impact on the overall figure for all cancers excluding non melanoma skin cancer. The NCRS have commented on the microscopic verification rates in England, noting that the relatively low percentage of prostate cancers that are microscopically verified corroborates that the increased incidence of prostate cancer is due to the increase in the numbers of prostate cancers being clinically diagnosed. Similarly, the relatively low percentage of haematological cancers that are microscopically verified corroborates the increase in clinically diagnosed haematological cancers registered by the NCRS.

Lung cancer continues to have fewer cases microscopically verified compared with the other major cancer sites. This is not unexpected because it is harder to biopsy a lung than some other sites, and because lung cancer is often diagnosed at a late stage when a biopsy would not change the clinically appropriate treatment.

Since the microscopic verification varies by cancer site/type, the figure for 'all cancers' combined is obviously influenced by the relative proportion of cancers in each country.

## Various Cancer Sites: 2013 (UK) & 2012 (Ireland) Microscopic Verification (%), Persons

Cancer Site	UKIACR Average	England NCRS	Scotland SCR	Wales WCISU	Northern Ireland NICR	Ireland NCRI
Lung	72.1	70.4	68.7	67.0	69.1	85.1
Breast Invasive	98.4	98.2	98.8	96.4	99.1	99.5
Breast In Situ	99.6	99.6	100.0	98.6	100.0	100.0
Cervix Invasive	97.3	97.5	98.1	95.3	97.1	98.6
Cervix In Situ	100.0	100.0	100.0	99.8	100.0	100.0
Melanoma of skin	99.1	98.9	99.9	96.5	100.0	100.0
Colorectal	89.3	88.3	89.5	83.3	89.6	95.9
Prostate	87.6	85.8	89.8	79.0	87.5	96.0
Bladder	87.3	90.8	87.7	74.9	90.3	92.8
Haematology	82.0	82.4	95.3	41.4	93.2	97.5
All excl. NMSC Male	83.4	83.1	83.5	73.4	84.5	92.6
All excl. NMSC Female	86.2	86.1	86.1	78.4	87.9	92.6

UKIACR averages were calculated using data from all countries in the table and are not weighted

### Mortality:Incidence (M:I) Ratios

Variations in mortality:incidence (M:I) ratios across the UK and Ireland may reflect changes in the efficiency of ascertainment or elimination of duplicate registrations by some registries (skewing the UK and Ireland average), the quality of mortality data, random variation, or genuine differences in survival patterns.

The M:I ratio for bladder cancer in Scotland is higher (0.68) than the UKIACR average (0.50). The SCR state that this ratio is dependent on the extent of misclassification between invasive and non-invasive tumours, both in the cancer registry and in mortality records. The NICR reported a M:I ratio that is also higher than the UKIACR average (0.59) and stated that there is strict application of the rules regarding bladder cancer registration at NICR, with the exclusion of pTa tumours (any grade) in bladder cancer statistics, which explains lower cancer incidence. The NICR completed a regional audit of bladder cancers diagnosed in 2011, which did not highlight any concern regarding data completeness.

The M:I ratio for Lung cancer in Wales (0.76) is lower than the UKIACR guideline (0.83) and is due to the decreasing trend seen in mortality in Wales accompanied by the incidence remaining stable over the past few years. This is also the case in Ireland (0.77), where according to the NCRI the higher numbers of lung cancers in males overall has resulted in the M:I ratio falling. The prostate cancer M:I ratio in Wales is also lower than the UKIACR guideline (0.26) and is due to the increase in incidence for prostate cancer in 2013 in Wales compared to previous years. Ireland is also below this level (0.15) and the NCRI have suggested that in Ireland the incidence rate for prostate cancer has increased dramatically over the last two decades, probably reflecting large-scale PSA testing of asymptomatic men. In tandem with this the prostate cancer mortality rate in Ireland has decreased significantly at 2.6% annually during 2001-2012.

The M:I ratio in Northern Ireland for invasive cervical cancer (0.20) is lower the UKIACR average (0.28). In NI the rate of cervical cancer often fluctuates due to calculations being completed on small numbers. For example, the incidence of cervical cancers ranged from 90 to 106 (2010-2013), with deaths ranging from 21 to 24 (2010-2013).

Scotland's M:I ratio for haematological neoplasms (0.49) is similar to those of Northern Ireland (0.47) and Ireland (0.48). These differ from the M:I ratios found in England (0.41) and Wales (0.40), though there does not appear to be a specific reason for the differences in this ratio between the countries.

## Various Cancer Sites: 2013 (UK) & 2012 (Ireland) Mortality:Incidence Ratio, Persons

Cancer Site	UKIACR Average	England NCRS	Scotland SCR	Wales WCISU	Northern Ireland NICR	Ireland NCRI
Lung	0.78	0.79	0.81	0.76	0.78	0.77
Breast Invasive	0.22	0.21	0.22	0.20	0.24	0.23
Cervix Invasive	0.28	0.27	0.29	0.33	0.20	0.33
Melanoma of skin	0.14	0.16	0.15	0.17	0.08	0.16
Colorectal	0.39	0.39	0.42	0.39	0.36	0.38
Prostate	0.22	0.23	0.28	0.20	0.26	0.15
Bladder	0.54	0.49	0.68	0.49	0.59	0.47
Haematology	0.45	0.41	0.49	0.40	0.47	0.48
All excl. NMSC Male	0.48	0.47	0.54	0.46	0.49	0.42
All excl. NMSC Female	0.44	0.44	0.48	0.44	0.44	0.42

UKIACR averages were calculated using data from all countries in the table and are not weighted

## COMMENTARY FOR COMPLETENESS OF THE DATASET

It should be noted that high levels of completeness of a data item do not necessarily guarantee the accuracy of the recorded information.

### Demographics and Diagnostic Details

Completeness of the dataset when considering demographics and diagnostic details was good across the majority of measures in the UK and Ireland. For seven out of the 13 measures, the average UKIACR performance score was 100%. The NCRI have highlighted two measures where the UKIACR average was 100% but NCRI achieved 99.9%. These measures were patient's address and date of death and NCRI have explained that this does not equate to a large number of actual cases (12 and 7, respectively) and also that despite there being a legal obligation to register a death within 3 months, this does not always happen and causes deaths to be recorded by the NCRI without any date of death.

The non-weighted UKIACR average completeness for ethnicity is low at 56.9% and neither the NICR nor the NCRI provide data on this measure. Ethnicity is entered on the WCISU cancer registry, but its completeness is low at 30.3%. Census data shows that the size of the ethnic minority population in Wales is relatively small, except for parts of Cardiff and Newport, and a few additional urban areas. Unfortunately, historically, the underlying primary and supplementary data sources currently used for cancer registration in Wales have very low completeness in their ethnicity fields. WCISU is currently exploring alternative routine sources to supply this data, but it may prove difficult,

Wales are lower than the non-weighted UKIACR average for type of growth (Wales: 82.0%, UKIACR: 88.2%) and basis of diagnosis (Wales: 90.7%, UKIACR: 97.4%), whereas the rest of the UK and Ireland achieved levels that were higher than the averages for both of these metrics. The WCISU suggested that the type of growth performance has decreased from last year due to the haematology coding issue described earlier. For the indicator basis of diagnosis, the WCISU has commented that the primary data source PEDW contains many records that are "not known." The 2014 cancer registrations currently being processed by WCISU now use the national cancer MDTs electronic patient record system as the primary data source with several other sources supplementing that. This new process should greatly improve the completeness of this indicator.

### Treatment Information

The completeness of data for patients recorded as receiving radiotherapy in Wales (11.1%) is lower than the non-weighted UKIACR average (20.5%). WCISU have stated that radiotherapy completeness is low because coded radiotherapy data within PEDW is only received from two of the three radiotherapy centres in Wales at present. However the completeness of this data should improve in the future with the imminent introduction of an all Wales Radiotherapy Dataset in 2015.

The completeness for recording of prostate cancer treatment is also low in Wales (44.2%) compared to the non-weighted UKIACR average (67.3%). The WCISU has stated the low hormone treatment completion figures (which contribute to the prostate any treatment measure) have resulted in the low treatment figures recorded for prostate cancer. This issue also impacts on all malignancies excluding non-melanoma skin cancer. WCISU is exploring new data sources, such as the cancer waiting time data and also working with others towards implementing a systemic anti cancer treatment (SACT) dataset in Wales, to try to rectify this for the future.

NCRI have found that the percentage of patients who have had hormone treatment for prostate cancer is under reported in their data. This is due to many hormone treatments occurring at outpatient level, making it difficult to capture the information. The under reporting is also the reason why the prostate cancer any treatment performance for Ireland is slightly below the non-weighted UKIACR average for those age between 0 – 64 (Ireland: 63.5%, UKIACR: 67.3%) and aged 65+ (Ireland: 62.3%, UKIACR: 67.4%). In Wales, the figure for those aged 0 – 64 is 44.2% and for those aged 65+ it is 34.5%.

Differences in the percentage of patients recorded as undergoing surgery may reflect differences in the definition of surgery rather than real differences in treatment activity so caution is required when interpreting these figures. The figure for Scotland (43.3%) is similar to the target (44.0%). Large variations in recorded treatment rates for prostate cancer suggest differences across the UK and Ireland in the definition of treatment.

Northern Ireland (23.1%) and Wales (23.3%) are both slightly lower than the UKIACR average for recording chemotherapy completeness data (24.9%). The NICR state that chemotherapy data are not available electronically from all health trusts in Northern Ireland, which may explain this lower level. The introduction of the new Regional Information System for Oncology and Haematology (RISOH) will help with the completeness of treatment information.

## **Screening Information**

Breast cancer screening performance is available from all UK countries. The proportion of people screen detected between the ages of 50 to 67 years is recorded highest in Northern Ireland (57.7%) and lowest in Wales (41.8%). The proportion of registrations for breast cancer with full screening history for those aged 50 to 67 years has much higher performance rates across all UK countries, with Scotland the highest (100.0%) and Wales the lowest (84.2%). The NCRS have commented that with the roll out of the national Breast Cancer Screening Histories tool (SHIM) data quality in England should continue to improve.

However, data for cervical cancer screening for those aged between 25 and 67 years is only available from England and Scotland, with Scotland (36.5%) having higher rates than England (27.4%). There is a known problem with the screen detected status for cervical cancers on

ENCORE. This is missing for some areas where the QARC did not submit data. The North West has returned a very high number of cases as 'screen detected'. The NCRS are investigating this further with the QARC. Despite these small pockets of missing or unreliable data, there are many more data feeds from many more QARCs than last year and in general the quality of the screening data has improved. The NICR has also commented on their lack of cervical screen detection information, stating that this information is problematic to collect as the screening programme is not centralised and many GP surgeries carry out their own call/re-call system. Clearly there is inconsistency across the UK and Ireland in collecting cervical screening data and this is further highlighted by the WCISU who commented that Cervical Screening Wales do not collect screening category as defined by the UKIACR and therefore this data is not available.

### **Site Specific Information for Breast Cancer**

The completeness of the dataset with regards to the site specific information for breast cancer is available across the UK and Ireland for 3 out of 4 measures. NCRI doesn't provide a figure for percent with a known NPI score.

Ireland has the highest proportion of breast cancer cases with known Bloom and Richardson grade (96.3%) whereas Scotland has the lowest (89.2%). Northern Ireland identified the highest proportion of breast cancer cases with a recorded known number of positive nodes (84.4%), whilst England had the lowest proportion (68.0%). The proportion of breast cancer cases with recorded known invasive size was also highest in Northern Ireland (90.6%) and lowest in Ireland (71.5%). Finally, the proportion of breast cancer cases with a known NPI score was recorded highest again in Northern Ireland (83.5%) and lowest in England (67.9%).

### **Detailed Stage Information**

The completeness of the dataset for detailed stage information was provided for males and females. For all invasive cancers (excluding NMSC), Scotland provided the lowest proportion cases with stage information (41.7%), whereas Northern Ireland provided the highest proportion of stage information (76.3%). Out of 13 specific cancer site groups that were measured (for example, breast, colorectal and gynaecological), Northern Ireland had the highest stage completeness for nine of the cancer site groups and provided stage data for more than 83% of cases. Scotland provided the lowest proportion of data, giving 0% for seven of the cancer site groups. However, staging data in Scotland are also collected for selected cancers via cancer audit. These data are used to monitor the Detect Cancer Early initiative in Scotland, and levels of staging completeness in cancer audit data have increased as a result of this. The range of cancers for which staging information is collected by the Scottish Cancer Registry is increasing over time, following the development of cancer Quality Performance Indicator (QPI) data sets in Scotland.

Staging completeness in Wales continues to show improvement with an increase of nearly three percentage points overall. Although the overall completeness of staging data remains below 70% in Wales, for certain cancer sites completeness is much higher. For example, breast staging is comparable to England, colorectal is over 80% and close to the UKIACR average, head and neck staging is higher than England and similar to Ireland, lung is well over 80% and exceeded only by Ireland, and Wales has the highest staging completeness for upper gastrointestinal cancers. Historically a large minority of Welsh residents are diagnosed and treated in England. Staging was not normally received on Welsh patient registrations received from the old English regional registries. This has a large impact on staging completeness in Wales. Recent and ongoing work undertaken with Public Health England colleagues regarding cross border exchange of staging data suggests this will enable Wales to exceed the staging target in future years. In addition, further staging data is also separately available in national audit data sets and in the MDT electronic cancer clinical record system in Wales. The latter is now the primary source for cancer registration year 2014 and onwards.

Northern Ireland provided stage information for 71% of sarcoma cases (from 51 cases), whereas all remaining countries had low levels of data completeness ranging from 32% in Ireland to 0% in Scotland. Haematological stage data are not collected in Scotland or Wales at the moment, and incompletely collected in Northern Ireland (0%, 0% and 5%, respectively), though this is much higher in Ireland (52%) and England (54%).

**Various Cancer Sites: 2013 (UK) & 2012 (Ireland)**  
**Completeness of the Dataset (%) - Stage Completeness By Cancer Site Groups, Persons**

Cancer Site	UKIACR Average	England NCRS	Scotland SCR	Wales WCISU	Northern Ireland NICR	Ireland NCRI
<b>All Invasive (excl. NMSC)</b>	64.8	70.8	41.7	64.5	76.3	70.6
<b>Breast</b>	77.7	84.6	46.7	84.2	93.9	79.1
<b>Colorectal (inc' anal canal)</b>	82.9	84.1	86.0	82.5	89.4	72.5
<b>Gynaecological</b>	66.8	78.6	42.3	53.9	87.1	72.2
<b>Haematological</b>	22.3	53.9	0.0	0.0	5.3	52.3
<b>Head &amp; Neck</b>	63.5	66.5	0.0	78.4	93.6	78.9
<b>Hepatobiliary &amp; Pancreas</b>	44.1	48.4	0.0	42.9	56.5	72.5
<b>Lung</b>	83.0	83.7	72.6	84.6	90.4	83.8
<b>Male Reproductive Organs</b>	60.6	58.2	0.0	62.7	97.5	84.6
<b>Malignant Melanoma of Skin</b>	72.6	87.1	0.0	86.3	98.7	90.7
<b>Prostate</b>	79.4	81.9	69.1	71.2	90.8	84.0
<b>Sarcoma</b>	31.0	31.3	0.0	21.3	70.6	31.5
<b>Upper Gastro Intestinal</b>	52.7	65.5	0.0	75.2	69.1	54.0
<b>Urological</b>	68.3	71.6	31.9	73.2	83.1	81.8

UKIACR averages were calculated using data from all countries in the table and are not weighted

## Conclusions

The UKIACR performance indicator data demonstrates the improvements made by each registry over the last year. The results show the combined number of cancer registrations (excluding NMSC) in England, Wales, Scotland, Northern Ireland and Ireland increased in 2013 compared to previous years and follows a continuing annual trend. Furthermore, the number of registrations varied both by cancer site and across the UK and Ireland. For example, there was an increase in the number of registrations for female breast cancer in situ in England (23.8%\*), Wales (25.1%\*), Northern Ireland (8.1%) and Ireland (6.0%).

The number of cervical cancers, both invasive and in-situ, rose in England (5.9%\* and 6.8%\*, respectively) and Wales (2.5% and 11.7%\*, respectively), Northern Ireland saw an increase in invasive cervical cancer (7.2%) and a decline of 14.9%\* for in situ cervical cancer. All remaining countries saw a decrease for both invasive and in situ cervical cancers (Scotland: -2.7% and -11.5%\*, respectively; Ireland: -15.0%\* and -1.4%, respectively; Northern Ireland: -14.9%\* for in situ cervical cancer).

There were statistically significant increases in the number of female lung cancers in Northern Ireland (14.0%\*), Ireland (11.7%\*) and England (3.0%\*) with a small non-significant increase in Scotland and small non-statistical decrease in Wales.

DCO rates met the overall 2% target for the majority of cancer sites in the UK and Ireland, though rates in England are still above the 2% target for both males and females across a number of cancer sites and for all cancers (excluding NMSC). The NCRS noted that whilst their DCO rates did not meet the overall 2% target, DCO rates have fallen for all cancer sites in England in 2013 compared to 2012. The potential increase in DCO rates was a known risk before migration.

An area with strong performance generally across the UK and Ireland was found for staging completeness. The proportion of registries that provided detailed stage information was more than 60% for all countries within the UK and Ireland except for Scotland which instead provided the lowest proportion cases with stage information (41.72%). Northern Ireland provided the highest proportion of stage information (76.3%) and out of 13 specific cancer site groups measured, Northern Ireland had the highest stage completeness for nine of the sites and provided stage data for more than 83% of cases. Scotland provided the lowest proportion of data, giving 0% for seven of the cancer site groups. Staging data in Scotland is collected for selected cancers via cancer audit and this data is used to monitor the Detect Cancer Early initiative in Scotland, and levels of staging completeness in cancer audit data have increased as a result of this. The range of cancers for which staging information is collected by the Scottish Cancer Registry is increasing over time, following the development of cancer Quality Performance Indicator (QPI) data sets in Scotland. It is expected that staging completeness will increase across cancer sites in Wales in future years, as

the primary data source for cancer registration will be available in the MDR electronic cancer clinical record system in Wales.

The PI measures illustrate a number of potential issues with cancer registration and data collection, highlighting some areas for improvement. However, 100% completeness of particular data items is no guarantee of 100% accuracy of data and should not be pursued at the expense of incomplete ascertainment. By highlighting such trends, the progress demonstrated this year will hopefully continue.

Staging data has improved remarkably but there is still more work to be done. In areas where countries have focussed their resources, the PI results are strong (for example, Northern Ireland's staging completeness performance). NICR were able to achieve increases in staging data this year as a result of additional staffing resources. This highlights a need in all registries to consider the resources required to enhance staging completeness in the future. NICR could share their experience of improved data collection for site specific and detailed stage information and other countries should continue to focus on improved staging completeness.

There are other areas where data completeness can be improved:

- WCISU, NICR and NCRI have low levels of data completeness for ethnicity.
- Following the migration, NCRS should once again prioritise reducing DCO rates.

Cancer registries could also better understand:

- the effect of bowel screening on the incidence of colorectal cancer
- the differences in the incidence and coding of haematological neoplasms between the different countries and the coding systems used by each registry
- ways of identifying screen detected cervical cancers and perhaps harmonising classifications to ensure comparability

To ensure that the performance indicators are as useful as possible in the future and fully capture emerging data requirements, it is recommended that:

- the classifications used for the PIs should be reviewed to enable better comparison across countries
- the Analysis Sub Group should discuss, agree (if possible) and recommend new treatment indicators to reflect the growing demand for better quality treatment data.