



# **United Kingdom and Ireland Association of Cancer Registries (UKIACR) Performance Indicators 2017 report**

**13 June 2017**

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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.

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 five UK and Ireland countries and another based on the population of the UKIACR as a whole. The latter is biased towards the English results due to England having a much larger population than other UK and Ireland countries.

It should be noted that not all stage and grade site specific indicators are directly comparable between countries as different ICD 10 codes have been used for some cancer groups. Some countries figures have also been revised following the initial submission and so some figures will not be consistent in data table 3 compared to other data tables due to cancer registration being a dynamic process and figures being updated on an ongoing basis.

Note that the mortality: incidence ratio for Ireland is based on 2014 data and the breast cancer screening completeness data for 2015 is based on a half years' worth of data (01/01/2015-30/06/2015), however the data submitted for 2014 is for the full year.

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

## Commentary for England

This year the National Cancer Registration and Analysis Service (NCRAS) registration team significantly improved in their processing time, completing 2015 diagnoses in October 2016 and giving the quality assurance team time to run their checks ahead of sign-off at the end of November. Therefore, data for this report were taken from an analysis snapshot taken at the beginning of December 2016 a month ahead of that permitted by the UKIACR submission schedule.

Improvement in registry creep from 2.1% in 2016 to 1% this year suggests that data are being captured in the relevant period; consistent with death certificate only (DCO) rates remaining low.

Overall staging rates continue to rise and at 80.4% have doubled since the move to a national system; a tremendous achievement. High values for average completeness of core patient (98.9%), tumour (97.5%) and treatment information (87.5%) indicate the depth of the data available too.

One area that is disappointing is the availability of cervical and bowel screening data. Since the move to Public Health England (PHE) there have been changes to the configuration and personnel in the Screening Quality Assurance Service which have resulted in difficulties re-establishing the routine cervical screening data exchanges many offices had in place previously. This issue may need escalation within PHE management structure. Access to bowel screening data has been hampered by personnel and resource issues within NCRAS which are now being addressed.

As mentioned in previous reports, stability of incidence has been affected by the migration to a single system which involved changes in coding practise and registration process as well as the introduction of a major data source in the Cancer Outcomes and Services Dataset (COSD) in 2013. With 2015 diagnoses we have now completed three years processing of data on a single system which should help improve the stability of incidence estimates. However, as with all new datasets, provision of COSD was variable for the first few years.

In conclusion, NCRAS is confident that the 2017 UKIACR report demonstrates that improvements in timeliness have not been achieved at the expense of data quality.

## Commentary for Scotland

This commentary is focused primarily on the Executive Summary table.

### Stability

Overall stability (-1.9%) is similar to Wales (-1.7%), although this conceals more striking changes for some specific cancers, such as cutaneous melanoma and cervix uteri (both increased in numbers by 12.6%). There is no obvious explanation for these changes in terms of data quality.

### Registry creep

The figure for Scotland (2.5%) is similar to most of the other UKIACR registries apart from England (1.0%). It is difficult to determine an 'ideal' figure for this indicator. For example, it is preferable to capture detailed information on late registrations than to have them assigned to later years as death certificate only registrations, or to fail to capture cases of indolent cancer.

### Staging

Since last year, following on from publication of further cancer audit/quality performance indicator (QPI) data sets in Scotland, we have added some cancer sites for which we are seeking to collect staging information. This has led to an increase in the proportion of staged cancers, although our proportion (60.8%) is still below the UKIACR average (69.4%). (Note that staging data in Scotland are also collected for selected cancers via cancer audit). Further sites have been added to next year's cancer registry data. On the basis that staging information for less than 70-80% of cases at a given anatomical site cannot really contribute to any meaningful analysis, we have concentrated on trying to maximise completeness at specific sites. For the main sites and/or those cancers for which there are screening programmes, staging completeness was as follows:

<b>Cancer site</b>	<b>Scotland</b>	<b>UKIACR average</b>
Lower GI	73.2%	81.6%
Lung	90.3%	84.2%
Breast	84.3%	84.9%
Cervix	91.8%	83.4%
Prostate	77.9%	79.9%

### **Average of core patient information complete**

The figure for Scotland (96.0%) is low because completeness of ethnicity was 67.8% 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 (96.4%) is identical to the UKIACR average.

### **Diagnosing hospital known**

The figure for Scotland (93.2%) is lower than the UKIACR average (96.1%) because we were asked to exclude GP practices where some skin cancers were diagnosed and excised.

### **DCO rates**

Consistent with previous years, Scotland has the lowest proportion of death certificate only (DCO) cases (0.4% compared with the UKIACR average of 0.9%).

### **Zero day survivors**

Scotland has the second lowest proportion of zero day survivors (0.8% compared with the UKIACR average of 1.3%).

### **Microscopically verified**

The figure for Scotland (84.2%) is similar to the UKIACR average (85.8%). Obviously, the proportion of microscopically verified cases depends to a large extent

on case-mix – for example, countries with a higher proportion of lung cancer cases might be expected to have a lower proportion of microscopically verified cases.

### **Non-specific [morphology] codes**

Scotland has a low proportion of non-specific morphology codes recorded (1.5% compared with the UKIACR average of 3.7%).

### **Grade [of differentiation]**

The proportion of cancers recorded with a known grade of differentiation is higher in Scotland (58.5%) than the UKIACR average (55.1%).

### **Treatment**

The figure for Scotland (69.8%) is similar to the UKIACR average (74.0%), although there may be differences in the definition of what constitutes treatment between the contributing cancer registries.

### **Breast Screening Data**

There is some variation between the countries. Scotland's figure of 48.1% of breast cancers detected by screening in the age range 50-64 years is similar to the UKIACR average (50.7%).

### **Bowel Screening Data**

Again, there is some variation between the countries (although data are not available for all the countries). Scotland's figure of 29.7% of bowel cancers detected by screening in the age range 60-69 years is not too different from the UKIACR average (23.7%) but differs considerably from the figure for England (17.0%).

### **Cervical Screening Data**

Once again, there is considerable variation between the countries (although data are not available for all the UK countries). Scotland's figure of 54.4% of cervical cancers detected by screening in the age range 25-60 years is very different from the UKIACR average (30.0%) and from the figure for England (13.8%). In an era when uptake of cervical screening may have been a little higher, a study in Southampton and South West Hampshire found that the proportion of screen-detected cases of

cervical cancer (invasive plus micro-invasive) in the age range 20-64 years was 43.5% (Herbert A, *et al.* *BJOG* 2009;116(6):854-9).

## Commentary for Wales

### Overview

The Welsh Cancer Intelligence and Surveillance Unit (WCISU) has demonstrated an incremental improvement across key indicators for 2015 despite working within the confines of the current outdated informatics system and the additional work involved in the migration to CAncer InTelligence Repository In Neoplasms (CATRIN). This is a credit to the dedication of the whole WCISU team.

The implementation of CATRIN in Wales will be the enabler for WCISU to exploit new datasets, provide facilities for data linkage opportunities whilst moving from the existing coding classification ICD 10 to the more appropriate and specific ICD-O-3 classification used by all the other UK and Ireland registries allowing greater comparability.

### Registrations

The number of registrations for all malignancies (excluding NMSC) decreased slightly in Wales for 2015 compared to the 2012-2014 average – this was statistically significant. This was similar to Scotland, but unlike other UKIACR countries. There are several possible explanations, including year-to-year random error, known registration creep and variation in it, or possible true emerging decreasing trends for some cancer types. For example, lower gastrointestinal cancers – one of the most common cancers - showed a relatively large statistically significant decrease in registrations in Wales in this period, not dissimilar to Scotland and Northern Ireland. There are some increases relating to non melanoma skins and it can be seen that Wales has a higher proportion of “other non melanoma skin cancers” compared to other countries due to less specific coding as this is not a cancer type that WCISU currently quality assure.

### DCO rates

The overall Wales DCO rate remains below the 2% target, and continues to be higher than all the other UKIACR countries, especially the better performing Northern Ireland and Scotland registries. This is the case for the four most common cancers,

as well as others such as upper GI. The probable reasons for this in Wales are multiple. These include a historic limited number, type, content and quality of underlying data sources up to and including 2015 registrations, along with historic similar cross-border registration issues between Wales and England for a large minority of Welsh residents whose pathway crosses to England. In addition, there are well documented issues of late diagnosis in Wales, also due to multiple factors. For 2016 registrations onwards, data sources and their content and registration processes, along with the timeliness, content and completeness of cross border registrations have been completely revised as part of the CATRIN implementation with PHE's ENCORE system. Throughout 2016 new early diagnosis initiatives have been emerging in NHS Wales – particularly, but not exclusively, for lung cancer – and these are set to continue in 2017 and beyond.

### **Late registrations**

The figure of 2.6% in Wales remains relatively high. As for DCO's this can be explained due to historic data, processes and cross-border issues, all of which have been renewed for 2016 data onwards.

### **Ethnicity**

The lack of ethnicity data remains a long standing issue for Wales. It is proposed to explore more innovative ways to source this data in the near future.

### **Microscopic verification rates**

Microscopic verification rates are lower in Wales compared to other UK countries. This is attributed to cancer registrations in Wales being historically up to and including 2015 registrations coded using ICD 10 version 4 which has no morphologies for haematological malignancies. It has been agreed that all 2016 year cancer registrations onwards will now be coded using the ICD-O-3 classification by WCISU. This will increase the microscopic verification rates.

### **Staging**

We have maintained the proportion of stage completeness for 2015 data as with 2014 data. For 2015 registrations, Wales' registration staging completeness is now only 5 percentage points away from achieving the target of 70% for all malignancies.

Stage completeness varies considerably by cancer type, but exceeds 76% for stage completeness for head & neck, lower GI, upper GI, lung, cervix, prostate, breast, melanoma, and thyroid and endocrine. Although, overall, Wales continues to lag behind England and Northern Ireland, the implementation of CATRIN and its associated revised data sources, processed and quality assurance reporting facilities, WCISU will be able to provide data completeness feedback real time to health boards/multi disciplinary teams in Wales not available at present. The combination of these factors will drive the increase in data completeness for stage for 2016 registrations onwards.

### **Grade**

The completeness of this performance indicator has significantly improved compared to the preceding registration year. This improvement is a result of our action plan to implement amendments to the data feeds received and the revisions made to cancer registration staff training. However, the grade completion in Wales remains considerably below other countries. The next phase of improvement will be addressed through the introduction of the new cancer registration system CATRIN and coding for 2016 registrations onwards. A greater improvement in grade completeness is expected thereafter.

### **Treatment data**

Treatment data completeness for Wales is lower than the UKIACR average. This is a historic situation related to the content and completeness of previous source datasets. The implementation of the CATRIN registration system, along with revisions to existing data extracts and the introduction of a new radiotherapy dataset (RTDS) and cancer waiting times (CWT) data sources for 2016 registrations onwards, will considerably improve registry completeness. It is anticipated further improvements will be evident in future years with the forthcoming addition of a new emerging Systemic Anti Cancer Treatment (SACT) dataset for Wales.

### **Screening category**

A review of WCISU business processes for the utilisation of screening data has commenced as part of the implementation of CATRIN. It is envisaged that this will enable an improvement in this area for 2016 registrations onwards.

## **Conclusions**

Although several PIs remain below average, WCISU has demonstrated continued year-on-year incremental improvements up to and including 2015 registrations in several areas despite working within the confines of the current outdated informatics system and data sources. This has also been achieved despite the considerable additional work involved in the migration to CATRIN and clinical coding training necessary to commence cancer registrations in ICD03. However these necessary investments will bring about a step change to the improvement of cancer registry PIs in Wales for 2016 registrations onwards.

## 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 the PRAXIS cancer registration system used by the NICR to ensure its stability. This has been successful and means that further development of PRAXIS can now proceed. The Cancer Patient Pathway System (CaPPs) is an administrative system which facilitates regional multidisciplinary team discussions for recording of clinical data items and diagnostic and treatment referrals. Although CaPPs doesn't feed directly into the PRAXIS system, the tumour registrars have live access and extracts can be downloaded from it. CaPPs has proved to be an extremely useful source for data and is integral to our cancer registration process.

### Registrations

A 2.5% increase on 2014 registrations submitted to the PIs in 2016, was noted by 2017. CaPPs is now used to identify possible cancers that were not part of the PRAXIS data feeds. It is hoped that employing CaPPs in this manner will reduce registry creep in the future.

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. For example, compared with the previous 3 years, there was a significant increase in incidence in 2015 of malignant melanoma in males but not in females. 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). The awareness campaign may also explain the significant increase in males (not females) seen in non-melanoma skin (NMS) cancers, for both basal cell and squamous cell carcinoma.

There was also a significant increase in the incidence of both in situ and malignant breast cancer, which may be due to better detection via the screening service, coincidental with the change from analogue to digital imaging completed at the end of 2014. In addition, there has been an increase in older women attending screening, as in 2015, a leaflet promoting screening in older women was produced and targeted at women over the age of 70 years.

A decreasing trend in colorectal cancer has been noted since 2012 which may be linked with the screening program; similar trends were seen in Scotland and Wales.

### **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. However, the 2% target was not met for cancer of the unknown primary (4.9%), which was also the case in each of the other jurisdictions. 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 0.6%, the percentage of zero day survivors for NI was well below the UKIACR average of 1.3%. One exception was cancer of the cervix, where the percentage was higher than the other jurisdictions at 2.5%. This is probably due to small numbers as the number of zero day survivors was less than five.

### **Microscopic Verification**

The NICR had a high level of microscopic verification (86.7%). Also, the percentage of non-specific of morphology codes was similar to other jurisdictions. A higher level was flagged for in situ breast, however this also relates to small numbers.

### **Demographics**

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

## **Treatment**

The NICR found the breakdown of treatment by tumour group to be a useful exercise, as last year it highlighted low capture of surgical treatment for malignant melanoma. As a result treatment data were supplemented from CaPPs for this submission, enhancing completeness. One area that still remains an issue is 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, with levels similar to that of England. However, in NI it is only captured in the first line of treatment data feed and as patients come on/off this pathway at various times, we would question its usefulness.

Although the figure for the percentage of cancers treated with palliative care in NI (8.3%) was similar to that of England (8.5%), it is most likely an underestimate as recording is incomplete on the systems that the NICR has access to.

At the time the data was frozen, not all of the OPCS codes had been processed for surgery, hence 92.6% for type of surgery known. This has now been completed and is at 100%.

## **Screening**

The NICR was able to supply screening data for breast, cervical and colorectal cancer, with the reported screen detection levels in 2015 similar to those in 2014 for both breast and colorectal cancer. The lower level of screen detected cervical cancers in 2015 will be investigated in conjunction with the screening service.

## **Staging**

The NICR has year on year improved the completeness of tumours staged and achieved a level of 82.4% which was well above the UKIACR target of 70%. The NICR registrars now 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 2015 improved to 61% and was above the UKIACR average of 55.1%. This is a great achievement as like stage, grade is not a 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 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.

## **Commentary for Ireland**

The National Cancer Registry Ireland is pleased to submit Performance Indicators for year of tumour incidence 2015 and for the first time we can provide information on breast screening.

### **Registrations**

As might be expected in a country where both the population and average age is increasing, the number of new cancer cases has increased almost year on year since 1994. In 2015 there was a rise of 2.4% in all invasive tumours (excluding non-melanoma skin cancers). The numbers of new cases registered have noticeably slowed since 2011 in the male population and less noticeably in the female population since 2009.

### **Melanoma**

Melanoma shows a significant increase at 16.5% overall and this continues a trend noted in the NCRI annual report published in December 2016 that melanoma “cases have increased steadily and significantly during the full period 1994-2014...Over-exposure to ultraviolet radiation, particularly through episodic skin exposure involving severe sunburn, is the main risk factor for melanoma of the skin. Melanoma incidence is highest in more affluent populations within Ireland, and the marked increases in melanoma incidence rates in Ireland are probably associated with increases in holidaying outside Ireland.”

### **Cervix invasive**

There has been a decrease in the numbers of invasive cervix cases over the last four years and this may be due to the introduction of the national screening programme in 2008.

### **Cervix in situ**

There has been an increase in the number of in situ cervix cancers for the first time in four years. This may be explained partly by an increase in the target population as noted in the CervicalCheck programme report for 2014-2015 “Coverage in the 5-year

period to the end of August 2015 increased to 78.7% of the target population of women aged 25 to 60 years of age from 77% at the end of August 2014.” September 2014 also saw women receiving an invitation for their third CervicalCheck screen for the first time which may also have contributed to the increase in 2015.

### **Bladder**

Upon investigating the significant increase in invasive bladder cancers we found 25 bladder tumours that were coded as invasive when in fact they were not. These have now been corrected on the NCRI system. If these corrections had been conducted prior to the data extract for the UKIACR report there would not have been a significant increase in the numbers of invasive bladder cancers overall or for either sex.

### **Cancer of unknown primary**

There was an increase of 22.1% in Cancers of Unknown Primary for the NCRI. At the time of data extraction 45% of the Cancers of Unknown Primary were created from death certs and electronic data sources all of which need to be reviewed. If the topography of the invasive tumour is not clear from the death cert or the electronic pathology data then the tumour is registered as a C80.9 tumour and awaits review by a Cancer Data Registrar (CDR). Over 55% of the Cancers of Unknown Primary had yet to be reviewed at the time of data extraction. Once reviewed many will be converted to a known primary tumour. As of January 2017 there has been a change of work practice in the NCRI and the tumours that require a topography and morphology review will be highlighted to the CDRs at an earlier stage in the registration process and a reduction in the numbers of Cancers of Unknown Primary for 2016 should follow.

### **Other invasive cancer**

The Other Invasive Cancers are similar to the Cancers of Unknown Primary in that 50% were created from death certs and electronic data sources and at the time of data extraction 52% of these had yet to be reviewed. The change in work practice should also have an impact on these cancers.

### **Percentage (%) of death certificate only cases (persons) for 2015**

The DCO rate in Ireland for the 80+ age group is high at 4% relative to the UKIACR country average of 2.7%. Many of the patients in the 80+ age group die in nursing homes and are difficult to follow up due a change of GP and a change of address from that given at registration. Since last year's report the NCRI put resources into reducing the DCO % in the 80+ age group which can be seen in the decrease from 6.3% in last year's report to 4% in this year's report.

### **Percentage (%) of zero survival cases (persons) for 2015**

The factors that impacted the DCO rate for the 80+ age group have also had an impact on zero survival for the 80+ age group.

### **Percentage (%) of microscopically verified cases (persons)**

Ireland is out of line with rest of the UKIACR with 66% of Cancers of Unknown Primary being microscopically verified. The delays in reviewing tumours created from death certs and electronic data have an impact on this percentage and it is anticipated that the percentage of Cancers of Unknown Primary with microscopic verification would fall back into line with the other countries once this process has been completed.

### **Completeness of dataset (%) demographics and diagnostic details**

The National Cancer Registry Ireland does not currently collect information on ethnicity or postcode.

### **Percentage (%) of cases treated with radiotherapy**

The percentage for Upper GI cancer treated with radiotherapy in Ireland is 25.3% versus an UKIACR country average of 16.6%. On review the data appears valid. The percentage for Ireland is up slightly from last year's report which was 23.3%; however it is not sufficiently different that it can be passed off as an anomaly.

The percentage of cases which had radiotherapy for Thyroid & other endocrine gland tumours in Ireland is 13.1% compared to the UKIACR average of 25.5%. On investigation 39% of the tumours at the time of data extraction were awaiting completion and were therefore missing treatment information. The Cancer Data

Registrar in one of the main radiotherapy centres in Ireland reviewed these registrations and as a result the percentage of radiotherapy increased to 22.6%.

### **Percentage of cases treated with hormone therapy**

The NCRI have ongoing issues capturing hormone therapy treatment information and the percentage of patients who have had hormone treatment is under reported in our data. The majority of hormone treatment is prescribed at outpatient level which makes it extremely difficult to capture adequately. This is reflected in the PI report with all xNMSC hormone therapy at 6.1% for Ireland versus a UKIACR country average of 11.9% and prostate at 14.9% for Ireland versus a UKIACR country average of 38.7%.

### **Specific cohorts where treatment completeness data is expected (%)**

#### **Percentage of children and young adults (0-24) group with cancer and underwent any treatment**

The delays in registration as well as difficulty in accessing medical oncology data all impact the ability of the NCRI to capture treatment information in a timely manner. The percentage of any treatment for Ireland for 0-24 age group two months after data extraction is 79.4%.

#### **Percentage of all haematological cancer patients who received any treatment**

As above

### **Staging**

Through work completed on assigning a summary stage in TNM7 the NCRI have managed to increase the overall staging percentage from 42.6% in last year's report to 58.1% this year. Backlogs of registrations in some of the larger hospitals and delays in processing electronic data continue to have a large impact on the timeliness of stage and treatment data.

## **Conclusions**

The official year end for the NCRI for year of incidence 2015 was 31st March 2017 at which point the data was 85% complete. The data for the PIs was extracted at the end of January. It is often only on completion of a case (review of medical chart) that information on clinical staging, chemotherapy, hormone therapy and certain demographic information will be recorded on the registration system. As a result the percentages for the NCRI for staging and treatment are low but these percentages will increase once the year has been completed.

## 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 large increases are seen in head and neck cancer, malignant melanoma and breast 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.

It is recommended that a revised template be prepared for the next set of performance indicators so that grade is calculated in Data Sheet 2 rather than in Data Sheet 3 as part of the staging completeness and guidance to be clearly stated how to calculate the proportion of cases with a stage at diagnosis.