



Victorian Lung Cancer Registry

Annual Report 2015





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Foreword

It is with great pleasure that I present the Victorian Lung Cancer Registry (VLCR) 2015 Annual Report.

Lung cancer remains a major disease burden in Victoria and requires a complex and multidisciplinary approach to ensure optimal care and outcomes. Since 2011, VLCR has been collaborating with clinicians, health services, researchers and consumers to capture clinical outcomes, and patterns and quality of care delivered to patients diagnosed with lung cancer in Victoria. VLCR is managed by the Department of Epidemiology and Preventive Medicine, Monash University, which manages more than 20 clinical registries.

Firstly, I would like to acknowledge and thank patients who have agreed to participate in the Registry. I would like also to thank members of the VLCR Steering and Management Committees, who generously volunteer their time to support this important project. At each of the participating sites, there are also clinical staff, data collectors and other hospital staff who make important contributions to VLCR and I thank them for their efforts. Finally, I would like to express gratitude to the Monash University team, including the Registry data collectors, the Monash University Cancer Research Program Staff and the Registry Sciences Unit for their assistance with the Registry. Special thanks go to the VLCR Project Manager, Margaret Brand and biostatistician, Breanna Pellegrini, who have put significant work into this report.

This 2015 Annual Report includes outcome data from eight participating hospital sites for patients diagnosed with primary lung cancer in the 2015 calendar year. The information in this report describes the progress of the VLCR and the commitment from clinical stakeholders to best practice and improving patient outcomes. The VLCR continues to develop and improve as it matures and we are committed to delivering better and more complete reports each year to fulfil the needs of various stakeholders.

Associate Professor Rob Stirling, FRACP

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Glossary

cTNM	Clinical stage of primary tumour	ICD 10	10th revision of the International Statistical Classification of Diseases and Related Health Problems (ICD AM)
pTNM	Pathological stage of primary tumour	NSCLC	Non-small cell lung cancer
PET	Positron emission tomography scan	SCLC	Small cell lung cancer
CT	Computed tomography scan	VATS	Video-assisted thoracoscopic surgery
ECOG	Eastern Cooperative Oncology Group Performance status score	VLCR	Victorian Lung Cancer Registry

Executive Summary

Lung cancer is the fifth most commonly diagnosed cancer in Australia.¹ The risk of lung cancer increases with age; it is estimated that the probability of an Australian being diagnosed with lung cancer by their 85th birthday is 1 in 17 (1 in 13 males and 1 in 22 females)¹. In Victoria, lung cancer is the largest cause of cancer-related death, killing more than 2000 Victorians per year, and representing 19% of all cancer deaths.²

Research that leads to earlier detection of lung cancer and new, more effective treatments will improve patient outcomes in the future, but for those already diagnosed, it is important to optimise the use of existing diagnostic and therapeutic options. Ensuring that all patients receive timely and appropriate diagnosis and treatment has significant potential to improve patient outcomes, usually without increasing health care costs. The VLCR aims to help health services to identify areas for improvement, by collecting consistent data across multiple health services and reporting on key process and outcome measures of the patient pathway. This enables regional and longitudinal performance evaluation. Importantly, these measures are risk-adjusted to account for differences in patient groups, and benchmarked, so that each participating health service can assess their performance relative to that of other providers. Benchmarked reporting from clinical quality registries has been demonstrated both nationally and internationally to improve quality of care by identifying gaps, facilitating planning and evaluating change

The VLCR is housed at Monash University in the Department of Epidemiology and Preventive Medicine, which acts as the custodian of the VLCR. Governance is provided by the VLCR Steering Committee, a group comprised of consumer representatives, clinical and technical expert advisors, participating clinicians and representatives from the State Department of Health, The Victorian Cancer Registry, Biogrid, Biobank and Monash University. Funding for this Registry comes from government, public and private sources.

The VLCR aims to recruit all newly diagnosed primary lung cancer cases over the age of 18 years attending participating hospitals. Data are collected at time of diagnosis, and at six months, two and five years post diagnosis. In 2015, eight hospitals participated in the Registry of which six were metropolitan, two regional; five public and three private. This comprised a total of 846 eligible and consented new Registry patients for 2015, bringing total VLCR recruitment to 2,878 patients since 2011.

Future initiatives for VLCR include expanding the VLCR across Victoria, with a goal to achieve state-wide inclusion and ultimately, a national lung cancer registry; continued refinement of quality indicators, development of additional indicators related to molecular treatment strategies; increased use of Registry data in new research initiatives; and publication of analysed patient-reported outcome data.

Rationale for Registry

Despite advances in imaging, surgery, chemotherapy, radiotherapy and targeted therapies, the survival rate for lung cancer lags behind other cancers, with an overall 5-year survival rate of 15% following diagnosis, and 1 in 100 for those diagnosed with advanced stage disease ^{2,3}. Aboriginal and Torres Strait Islander 5-year survival is only 7%⁴.

Diagnosis and management of lung cancer is becoming increasingly complex and expensive as new therapies become available. Also, there is evidence to suggest there is significant variation in access to care, care provision and outcomes in Victoria⁵. Ensuring that all Victorians receive safe, timely, appropriate, consistent and evidence-based care after a lung cancer diagnosis has substantial potential to improve patient outcomes. In order to achieve this, we need risk-adjusted, population-wide benchmarking of clinical data and the VLCR has the capacity to fill this need. In addition, as highlighted by the recent Targeting Zero report ⁶, in order to increase patient safety, health services need to become more accountable for the care they provide.

The VLCR provides benchmarked reports to inform clinicians, administrators and hospital Boards of measures of patient care at each site, including timely patient assessment and diagnosis; adherence to 'best practice' patient investigation and treatment pathways and patient outcomes. Importantly, Registry data are risk-adjusted to account for important patient differences, so that hospital results can be more fairly compared. The Registry consults with clinicians in the design and management of the project, acknowledging that clinician engagement is critical to both the operation of the Registry and the impact of its findings on clinical practice.

Registry Collaborators

The VLCR is designed to help improve the quality of care delivered to Victorians with lung cancer. The pilot VLCR was established in 2011 through funding from the Victorian Department of Health and was led by a broad-based governance committee that included medical and surgical clinicians, radiation oncologists, lung cancer specialist nurses, epidemiologists, and cancer research organisation representatives. Eight Victorian hospitals were initiated and staff trained to collect standardised data: six metropolitan and two regional; five public and three private. Following the initial pilot, the VLCR is now an ongoing population-based clinical quality registry that aims to record all newly diagnosed lung cancer cases in participating sites in Victoria. An additional four sites are participating as of 2016. The Registry focuses on the adult population seen in key lung cancer referral centres and will ultimately include smaller centres of care. Information from the Registry is used to monitor care provided including treatment, complications and both short-term and long-term outcomes of care. This information will be used to help identify trends and whether gaps exist in service provision.

Registry Governance

Monash University Department of Epidemiology and Preventive Medicine (DEPM) is the custodian of the VLCR. The VLCR governance structure includes a Steering Committee and Management Committee described in Appendices A, B. The VLCR Steering Committee comprises project investigators, senior clinicians, senior registry and clinical informatics and data management staff from the DEPM and two consumer representatives with personal experience of lung cancer. The Steering Committee provides oversight of the Registry's activities including ensuring that the quality of data is monitored and that policies are established to address issues of clinical interest or significance that may arise, including those relating to quality of care. The Management Committee is responsible for managing day-to-day aspects of the clinical registry. Data quality measures are reported regularly to the Management Committee.

The VLCR has developed a range of data management, access and escalation policies, and is supported by Monash University IT and security infrastructure. Appendix C summarises the VLCR escalation policy.

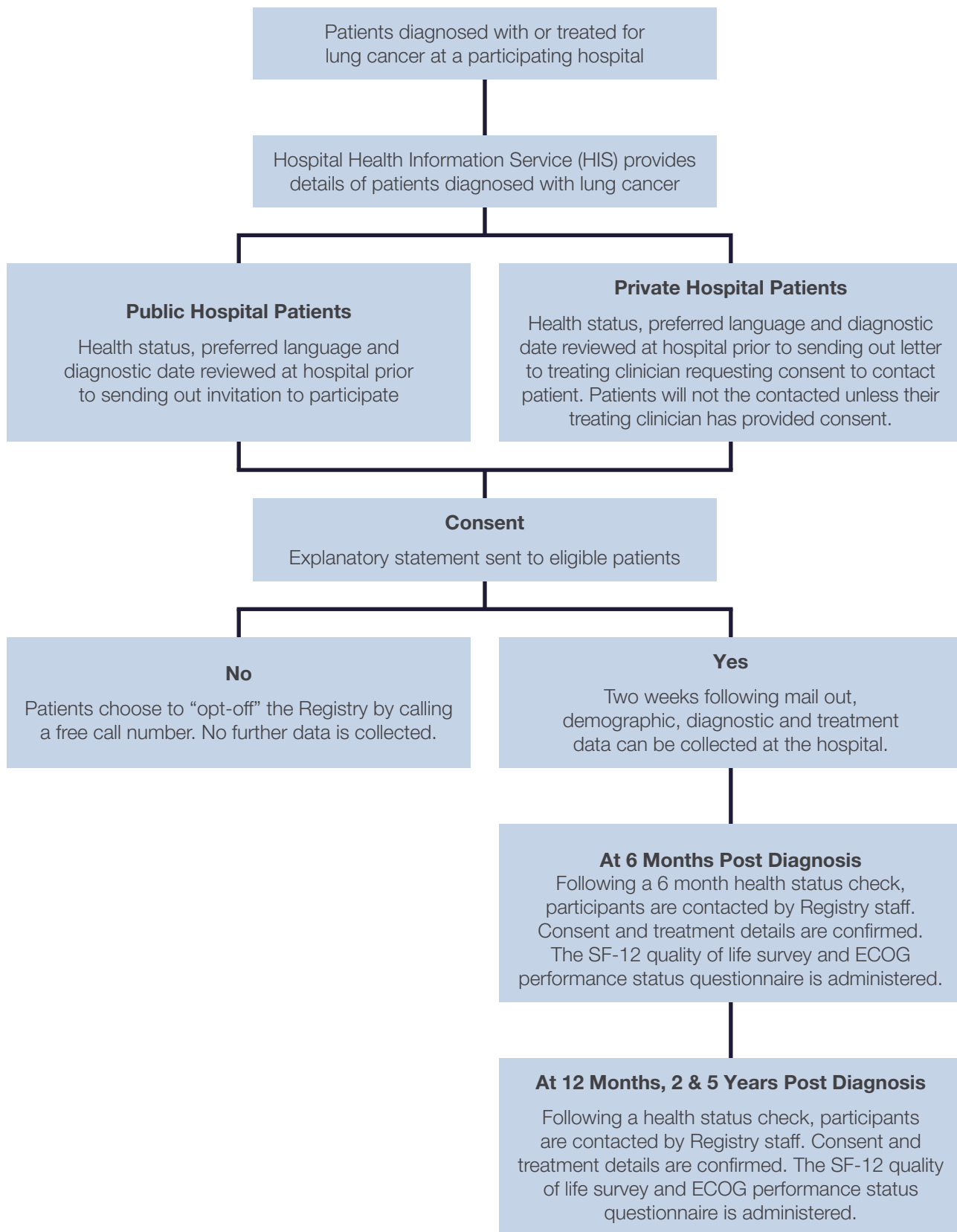
Registry Methodology

All patients over the age of 18 with a principal diagnosis of lung cancer, who have been admitted to hospital within the time frame specified, are eligible for inclusion in the VLCR. Exclusion criteria include: patients who present with secondary lung cancer, mesothelioma, progressive disease diagnosed before the specified commencement date, and those who have contacted the Registry to opt out. Potential Registry participants receive an explanatory statement which provides them with information detailing the purpose of the Registry, what participation involves, and what data will be collected. Invitees are given two weeks to 'opt-off' the Registry before collection of clinical and personal data commences. Patients have the option to withdraw their consent to participate in the Registry at any time.

Data collection for the VLCR occurs in a number of stages:

- **Stage 1:** Patients diagnosed with a principal diagnosis of lung cancer are currently identified through coded admissions data at participating sites. The medical record is then reviewed to identify the health status and the date of diagnosis of the patient, to enable an explanatory statement to be sent to eligible patients.
- **Stage 2:** Data collection occurs following expiration of the two week opt-off consent period. At this point the patient demographic data is imported into the Registry and key clinical information is collected from the medical record.
- **Stage 3:** Six months following the diagnosis of lung cancer, a general quality of life (SF12) questionnaire and a brief question about performance status (ECOG) is administered.
- **Stage 4:** Twelve months, two and five years following the diagnosis of lung cancer, patients will be telephoned by Registry staff to reconfirm consent and assess their progress. A general quality of life (SF12) questionnaire and a brief question about performance status (ECOG) will be administered. Health status is checked before a phone call is made.

FIGURE 1: VLCR DATA COLLECTION PROCESS



REGISTRY REPORTING

Data Period

The VLCR has provided detailed Quality Indicator reports to sites for the years 2011–12 and 2012–13 and 2015. This is the first Annual Public Report. The data contained in this document was extracted from the Victorian Lung Cancer Registry and pertains to data submitted for patients diagnosed with primary lung cancer from 1st January to 31st December 2015. Additional cumulative data collected from 2011 has also been included to show registration trends for participating sites. As the Registry does not capture data in real time, there can be a lag between occurrence of an event and capture in the VLCR.

Registry Site Participation

Table 1 below shows the total number of participant registrations by year, since the Registry commenced in 2011 (n=2,878). Table 2 lists the total number of participant registrations by site, from the date of inclusion in the Registry to 2015. Figure 2 lists the cumulative registrations from 2011–2015.

Table 1 VLCR patient registrations by year 2011–2015

Diagnosis Year	Number	Percent
2011	76	2.6%
2012	406	14.1%
2013	773	26.9%
2014	777	27.0%
2015	846	29.4%
Total	2,878	100%

Table 2 VLCR patient registrations by site 2011–2015

Notifying Institution	Number	Percent
Alfred Hospital	537	18.7%
Austin Hospital	628	21.8%
Cabrini Health	291	10.1%
Epworth Health	317	11.0%
Geelong Hospital	306	10.6%
Latrobe Regional Hospital	218	7.6%
St Vincent's Public Hospital	427	14.8%
St Vincent's Private Hospital	154	5.4%
Total completed data as at Dec 2015	2,878	100%

Figure 2 Accumulation of VLCR registrations 2011–2015



SURVIVAL ANALYSIS

2011–2015 REGISTRATIONS

The Victorian Registry of Births, Deaths and Marriages provides the VLCR with Death Register Data. Kaplan-Meier estimates of survivorship using 2011-2015 VLCR registrations are presented in Figures 3-6 and Table 3.

Figure 3 VLCR Survival analysis—total cohort

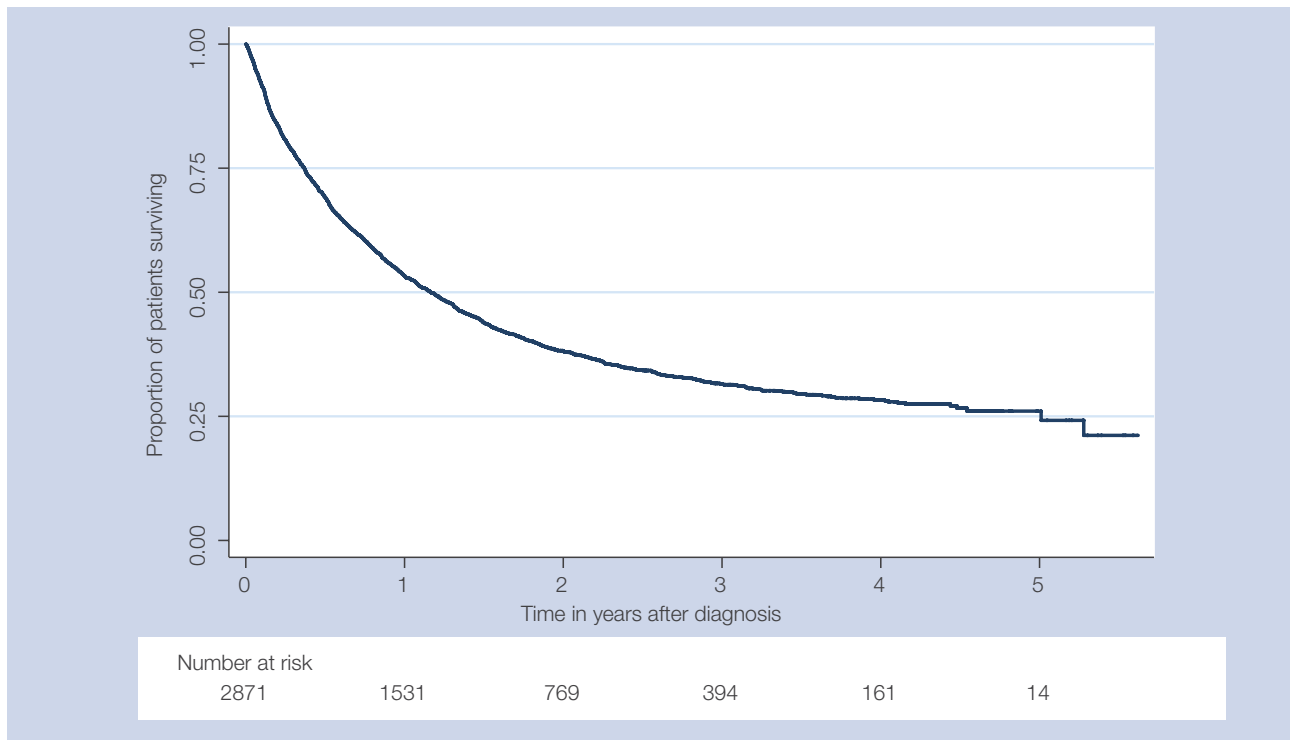


Figure 3: Median survival time for patients is one year and two months after diagnosis (Median 1.16 years; Interquartile Range 0.37-5.01).

Table 3 Percentages of survival at time intervals after diagnosis

Time after diagnosis	1 Year	2 Years	3 Years	4 Years	5 Years
All patients					
Survival % (95% Confidence Interval)	53.3% (51.5, 55.1)	38.1% (36.3, 39.9)	31.6% (29.7, 33.5)	28.3% (26.3, 30.4)	26.1% (23.5, 28.7)
By Sex					
Female Survival % (95% Confidence Interval)	56.7% (53.9, 59.4)	40.9% (38.0, 43.7)	34.7% (31.8, 37.7)	31.4% (28.2, 34.7)	28.6% (24.1, 33.3)
Male Survival % (95% Confidence Interval)	50.8% (48.3, 53.2)	36.0% (33.6, 38.4)	29.2% (26.8, 31.7)	26.0% (23.4, 28.6)	24.1% (21.1, 27.2)

Table 3: Lung cancer survival for VLCR patients was 53.3% at one year after diagnosis and 26.1% at five years after diagnosis.

Figure 4 VLCR Survival analysis by sex

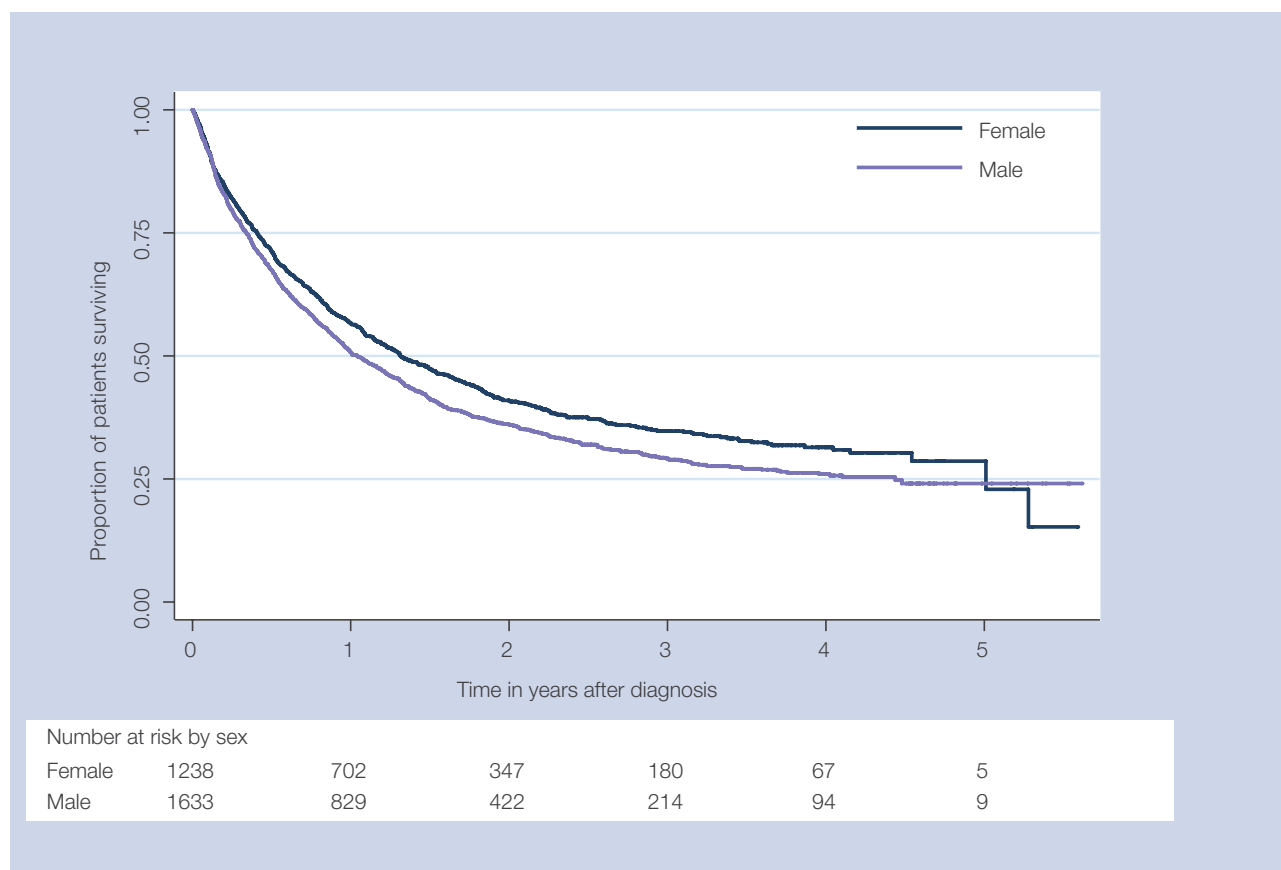


Figure 4: Female survival was slightly better at five years (28.6%) than male survival (24.1%). Median survival time is about three months longer for females (Female: Median 1.31 years; Male: Median 1.04 years).

Figure 5 VLCR Survival analysis by age group

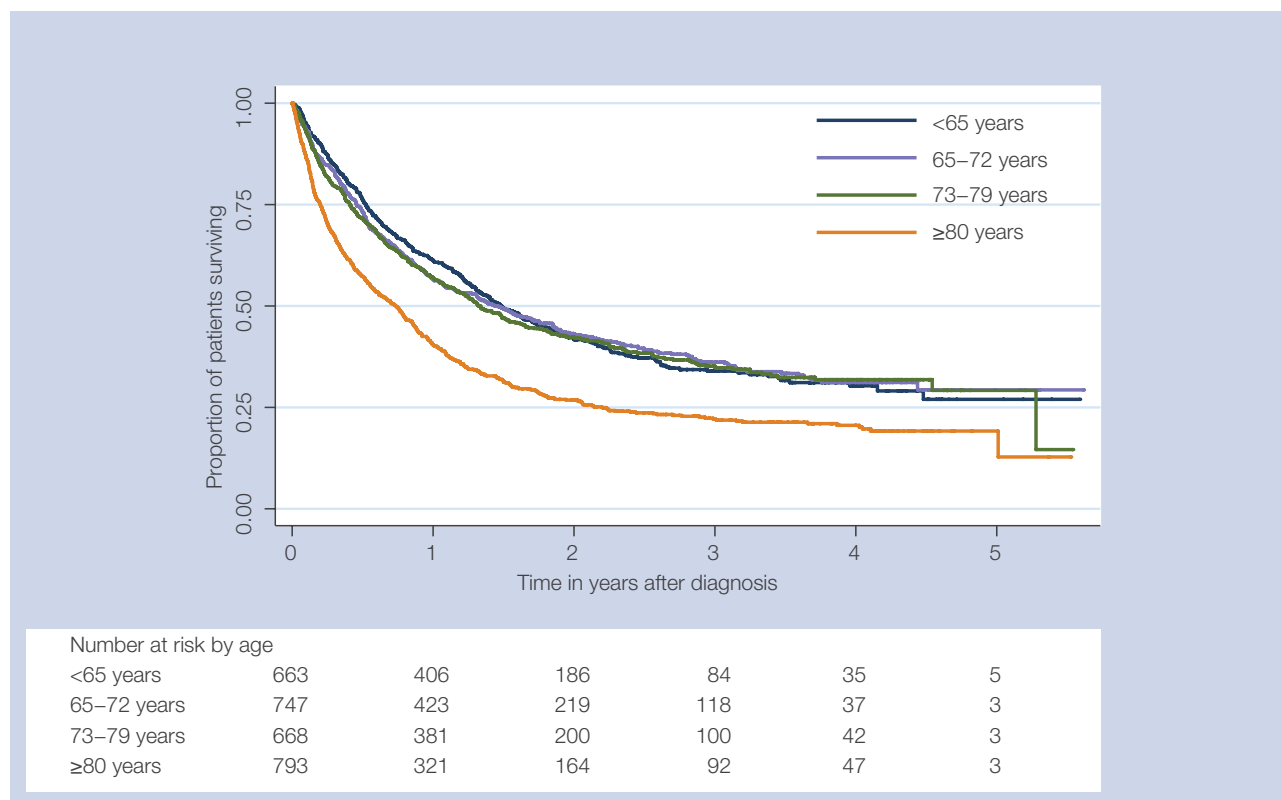


Figure 5: Survival rates are lower for patients diagnosed after 80 years of age; survival at one year for the 80 years and over cohort is just 40.5%, whereas survival at one year for those diagnosed before 65 years of age is 61.2% .

Figure 6 VLCR Survival analysis—total cohort by clinical stage

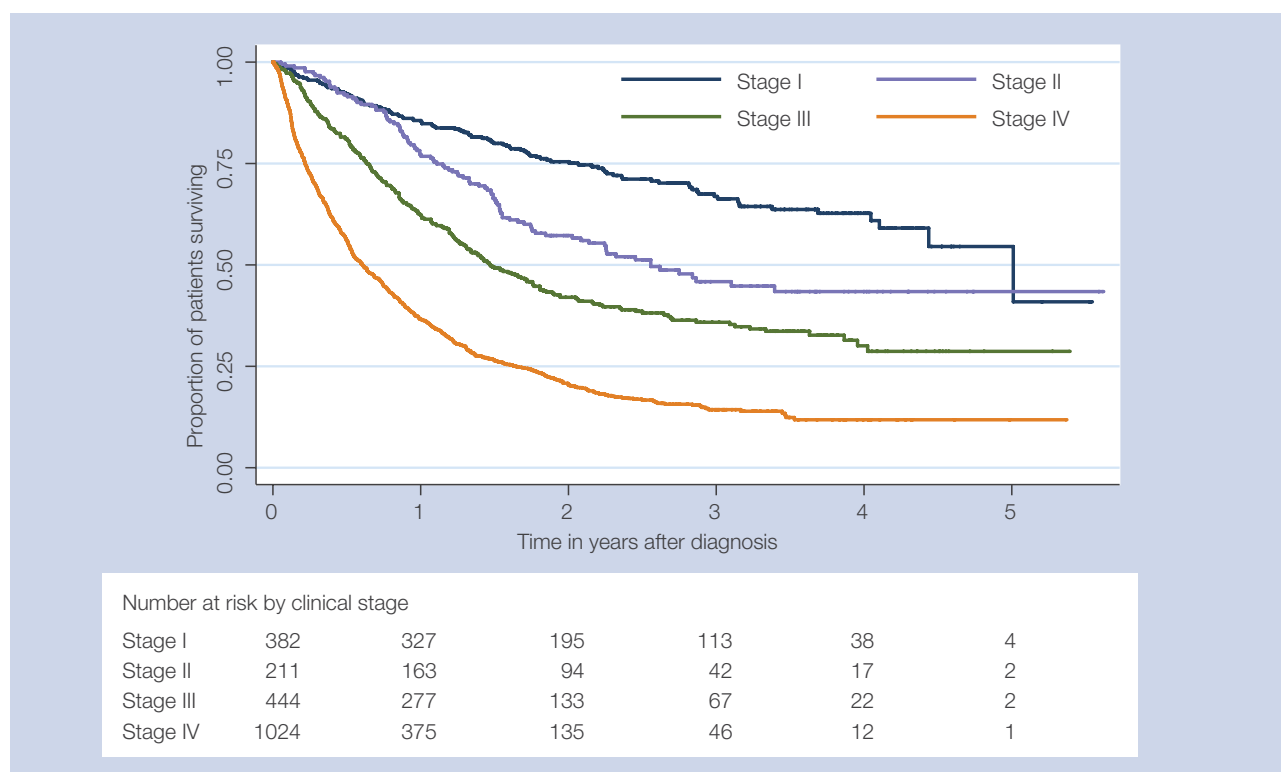
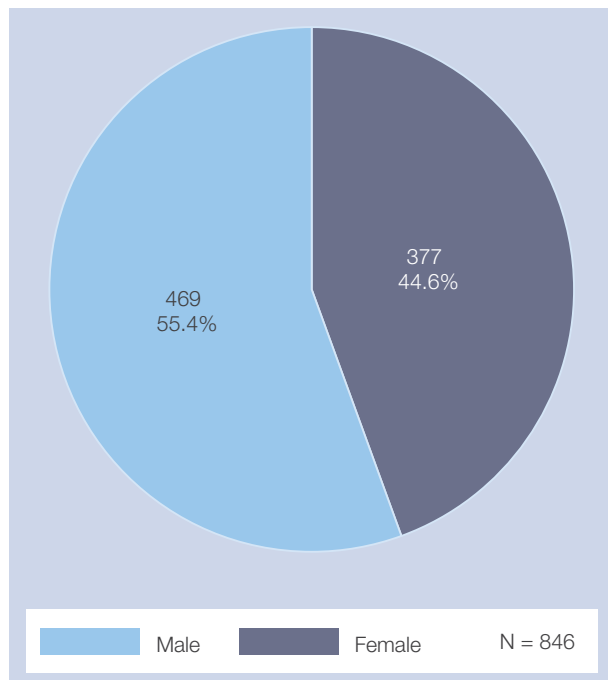


Figure 6: Survival rates are also lower for patients presenting at a later clinical stage; survival at one year for Stage I patients is 85.6% and only 36.6% for Stage IV patients.

VLCR PATIENT CHARACTERISTICS 2015

Sex, Age, Indigenous Status, Preferred Language.

Figure 7 VLCR 2015 Patient sex profile



In the 2015 period there were a greater number of male than female participants (55.4 vs 44.6%).

Table 5 VLCR 2015 Patient country of birth

County of birth (N=846)	Number	Percent
Australia	490	57.9%
Italy	47	5.6%
England	41	4.8%
Greece	18	2.1%
Scotland	17	2.0%
China	13	1.5%
Malta	11	1.3%
Croatia	10	1.2%
Netherlands	8	0.9%
Unknown	191	22.6%

In 2015, 57.9% of VLCR participants were Australian born. Italy, England, Greece and Scotland were the most frequent countries of birth for non-Australian born participants.

Table 4 VLCR 2015 Patient indigenous status

Indigenous Status (N=846)	Number	Percent
Indigenous	10	1.2%
Non-Indigenous	778	92.0%
Unknown	58	6.9%

In 2015, only 1.2% of participants identified themselves as Indigenous Australians.

Table 6 VLCR 2015 Patient preferred language

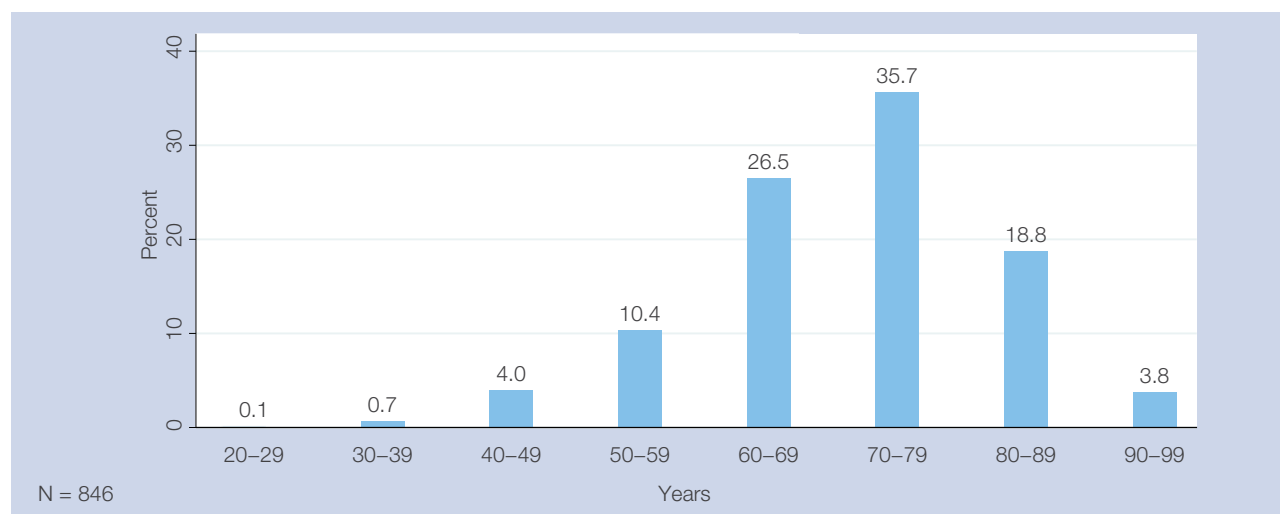
Preferred language (N=846)	Number	Percent
English	756	89.4%
Italian	12	1.4%
Greek	9	1.1%
Cantonese	8	0.9%
Mandarin	5	0.6%
Macedonian	4	0.5%
Chinese	3	0.4%
Croatian	3	0.4%
Serbian	3	0.4%
Unknown	43	5.1%

In 2015, English was identified as the first language by 89.4% of participants.

Table 7 VLCR 2015 Patient age grouping by sex

	Female (N=377)		Male (N=469)		p-value (test)
Age					
Mean (Standard Deviation)	69.6 (11.9)		71.1 (10.6)		0.002 (Two sample t-test)
Median (Interquartile Range)	71 (62, 78)		72 (65, 80)		
Age Group					
20–29 Years	1	0.3%	0	0.0%	0.047 (Pearson's chi-squared)
30–39 Years	3	0.8%	3	0.6%	
40–49 Years	21	5.6%	13	2.8%	
50–59 Years	50	13.3%	38	8.1%	
60–69 Years	96	25.5%	128	27.3%	
70–79 Years	133	35.3%	169	36.0%	
80–89 Years	60	15.9%	99	21.1%	
90–99 Years	13	3.4%	19	4.1%	

Male participants were older than females at diagnosis (71.1 vs 69.6; $p=0.002$), and males were more likely to present in advanced age groups (> 60 years; $p=0.047$)

Figure 8 VLCR 2015 Patient age profile

The highest age at diagnosis incidence is in the 70-79 year age group (35.7%), with those diagnosed prior to 60 years of age representing 15.2% of registrations.

LUNG CANCER TYPES IN REGISTRY

The total number of patients categorised according to cancer cell type is presented in Figure 9 below. Overall Non-Small Cell Lung Cancer (NSCLC) was the most frequent histology identified at 83.1% and Small Cell Lung Cancer (SCLC) comprised 9.9% of Registry participants. Lung cancer type was not identifiable for 1.5% of participants. Documentation of clinical stage was not recorded for 137 (19.5%) of 703 NSCLC participants.

The majority of NSCLC patients participants with available staging at diagnosis had advanced metastatic disease at presentation (51.8%), while just 30.1% had localised, early stage disease (Stage I-II) (Figure 10). Documentation of performance status was unavailable for 43.7% of participants, however amongst the 476 reported participants 366 (76.9%) had good performance status (ECOG 0-1) and 110 (23.1%) had poor performance status (ECOG \geq 2) (Table 8).

Figure 9 VLCR 2015 Lung cancer type profile

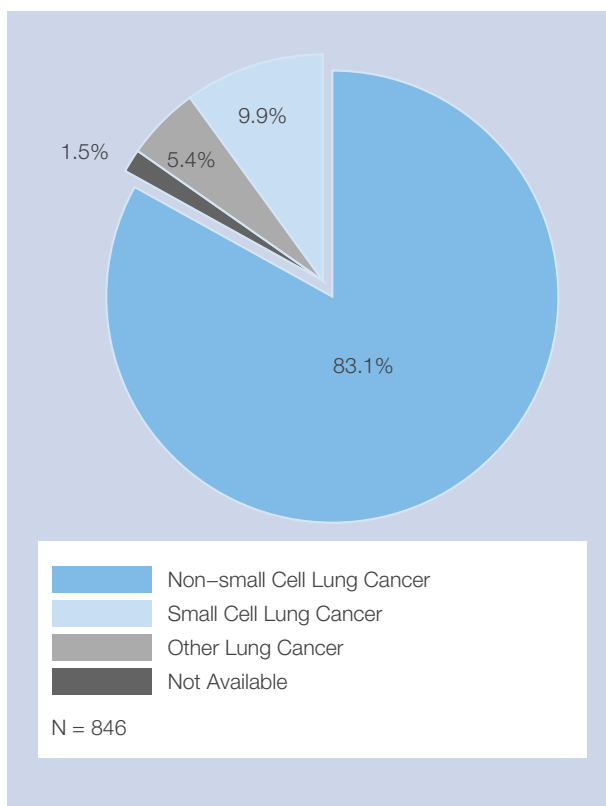
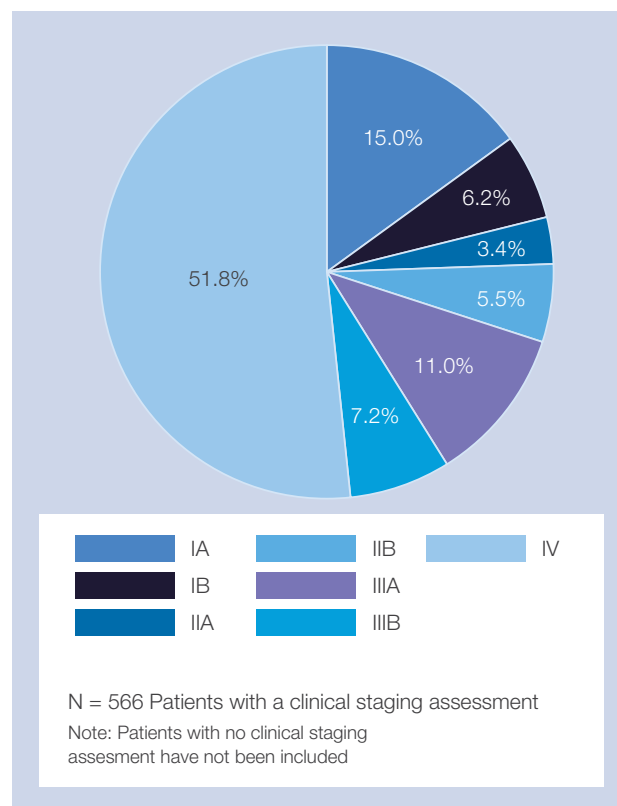


Figure 10 VLCR 2015 Clinical staging for NSCLC patients



PATIENT PERFORMANCE STATUS

Table 8 VLCR 2015 Patient ECOG status at diagnosis

ECOG status at diagnosis (N=846)	Number	Percent
0—Fully active, able to carry on all normal activity without restriction	139	16.4%
1—Restricted in physically strenuous activity but ambulatory and able to carry out light work	227	26.8%
2—Ambulatory and capable of all self-care but unable to carry out any work activities.	75	8.9%
3—Unable of only limited self-care, confined to bed or chair more than 50% of waking hours	32	3.8%
4—Completely disabled. Not able to self-care. Totally confined to bed or chair	3	0.4%
Unknown	370	43.7%

CLINICAL QUALITY INDICATORS

The VLCR collects and reports on data relating to 23 clinical quality indicators. These indicators have been developed by an expert working group comprising representation from thoracic surgery, respiratory medicine, medical oncology, radiation oncology, palliative care and epidemiology following an extensive review of Australian and international clinical practice guidelines (see Appendix D)

The VLCR indicators are risk-adjusted and benchmarked against the cohort, and then reported to participating sites for the purposes of quality improvement. Currently, this is undertaken annually, although as the Registry expands, and registrations grow, this may increase to 6-monthly. Individual sites only have information regarding their data, and where the site may be identified as an outlier, processes are in place to validate the data and for the site to review their internal processes. A selection of the clinical quality indicators is presented below.

How to interpret Funnel Plots

Clinical registries often report benchmarked clinical data as funnel plots, which allows for the level of confidence in the data to be incorporated within the graph. When interpreting funnel plots (see example in *Figure 11*), the horizontal axis (x-axis) measures the number of cases being examined. In this report, the number of cases reflects the number of subjects at the institution for the particular indicator. The vertical axis (y-axis) measures the percentage of cases that meet the clinical indicator being reported. For example, this might represent the percentage of cases where documentation of clinical stage was recorded in medical records by hospital group, or the percentage of cases with documented ECOG status recorded in the medical record.

A point estimate (represented by the black dot) plots the number of observed cases by percentage of cases meeting the indicator for each hospital group contributing to VLCR. The larger the number of cases (volume) notified to VLCR, the further to the right will be the black dot, the smaller the volume, the further to the left its black dot will be.

The blue line represents the pooled average (percentage meeting the indicator) of observed cases for all hospital groups combined. As the number of patients gets larger, the 95% and 99.8% control limits narrow.

Common cause variability is a source of variation caused by unknown factors that result in a steady but random distribution of output around the average of the data. Common cause variation is a measure of the process's potential, or how well the process can perform when special cause variation is removed. Common cause variation is usually associated with outcome measure variation less than 2 SD of the benchmark.

Special cause variation (aka assignable cause variation) is a shift in output **caused** by a specific factor such as environmental conditions or process input parameters. It can be accounted for directly and potentially removed, and is a measure of process control. Special cause variation is usually associated with greater than 3 SD of the benchmark.

We undertook **risk-adjusted** funnel plot analysis because the VLCR is an observational study design and we wanted to account for potential confounders. Patient sex, age, birthplace and clinical staging assessment were determined to be clinically important and were included in all risk-adjusted funnel plots except where otherwise specified for reasons such as colinearity, sparseness of numbers meeting the indicator, as well as sample size restrictions within the indicator definition.

Interpretation of results for outliers in funnel plots should be treated with caution if:

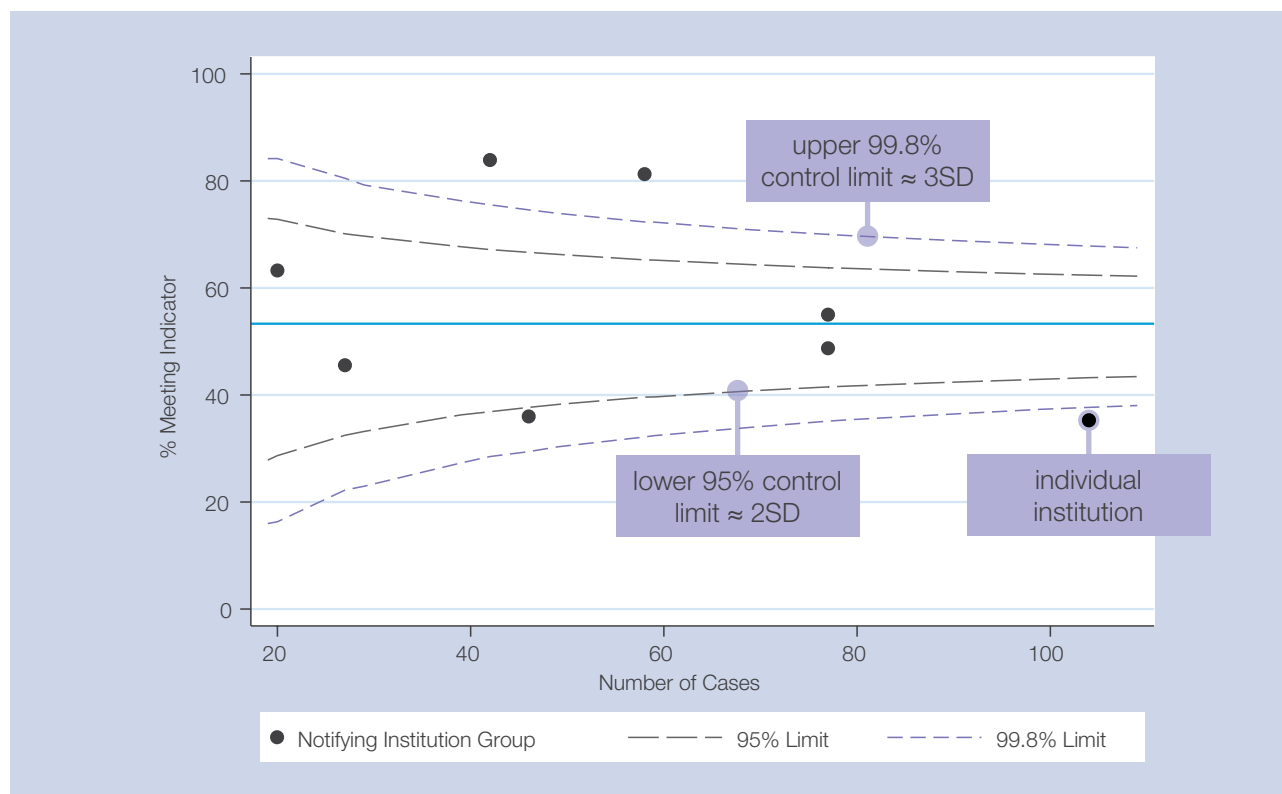
- More than half of the hospitals have less than 50 patients with available data for the indicator; or
- Overall data completeness for the relevant indicator is less than 80%

Selected Quality Indicators

The following quality indicators are grouped to reflect six specific aims to improve core quality of health, by delivering health care that is: **safe, effective, patient-centered, timely, efficient and equitable**⁷.

Appendix D lists data used to calculate each quality indicator. Indicators are presented as crude (non-adjusted) and risk adjusted by sex, age, birthplace and clinical staging assessment. Participating sites are de-identified and represented by numbers 1–8.

Figure 11 Funnel plot example and interpretation



SAFE HEALTH CARE

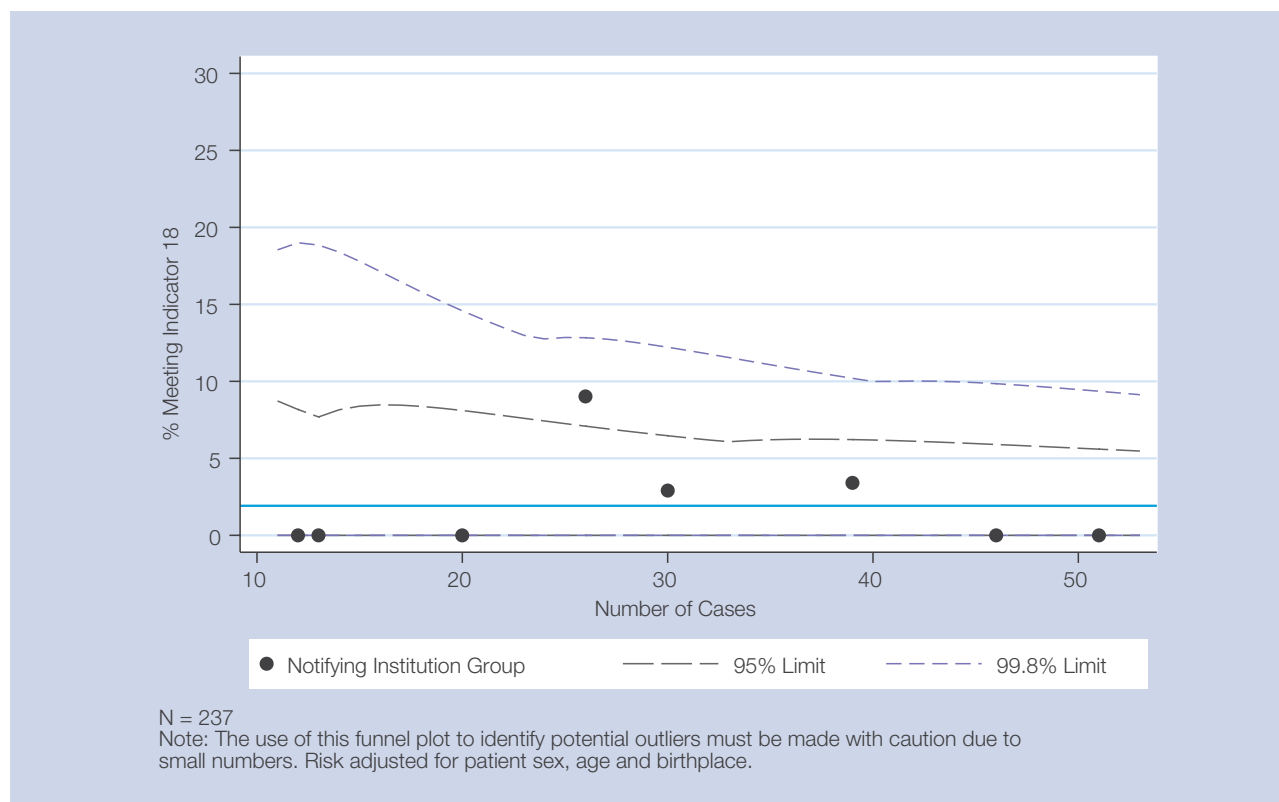
Degree to which health care processes avoid, prevent, and ameliorate adverse outcomes or injuries that stem from the process of health care itself

Table 9 Proportion of patients with NSCLC who have had a resection and date of death within 30 days of surgery (Quality Indicator 18)

SITE	1	2	3	4	5	6	7	8	TOTAL
Numerator	1	0	0	2	2	0	0	0	5
Denominator	30	46	51	26	39	20	12	13	237
Meeting indicator (crude)	3%	0%	0%	8%	5%	0%	0%	0%	2%
Meeting indicator (risk-adjusted)	3%	0%	0%	9%	3%	0%	0%	0%	-
Data completeness	93%	98%	100%	100%	90%	100%	100%	100%	97%

Note: Surgical resection includes pneumonectomy, lobectomy, segmentectomy and wedge resection

Figure 12 Proportion of patients with NSCLC who have had a resection and date of death within 30 days of surgery (Quality Indicator 18)



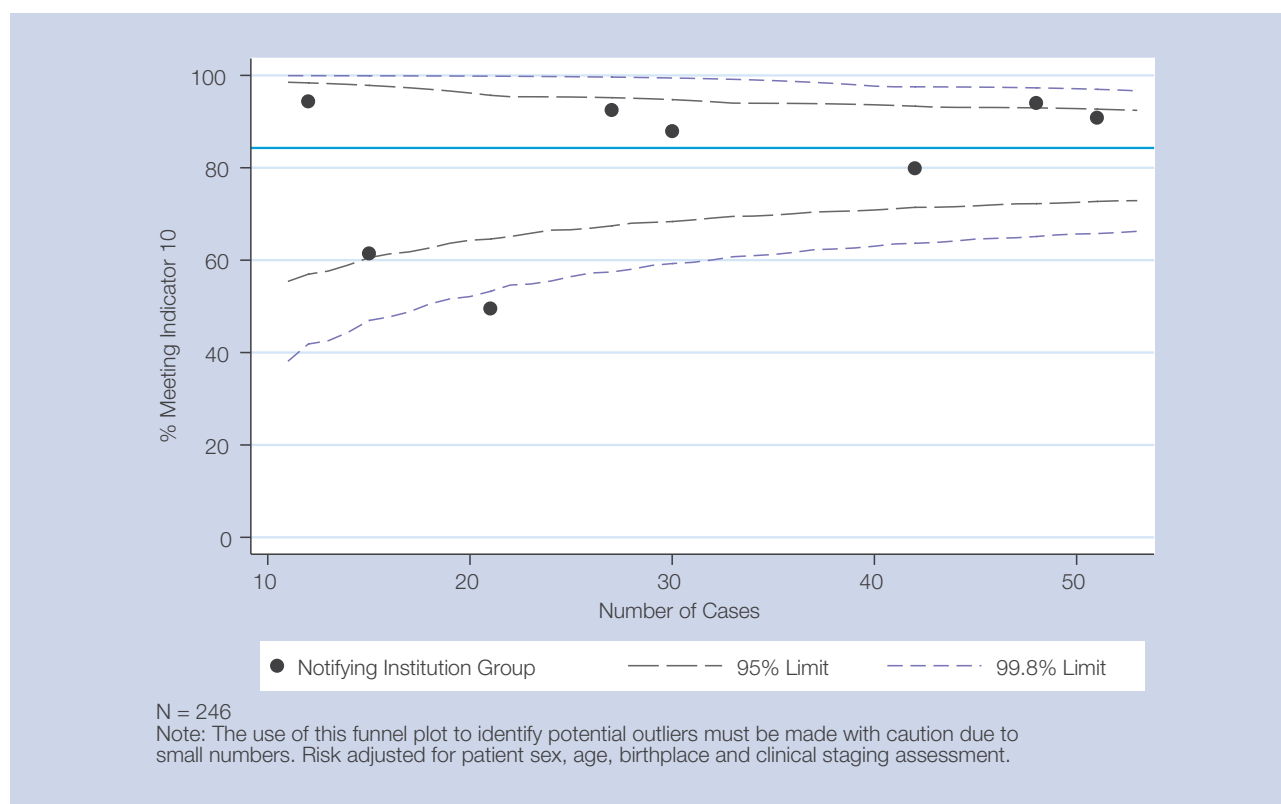
This funnel plot has been included in the 2015 report for completeness and consistency, but must be interpreted with caution. Due to small patient numbers, this indicator could only be risk-adjusted for patient age, sex and birthplace. As sample size increases in future reports, we will aim to develop and incorporate a comprehensive risk-adjustment model.

Table 10 Proportion of patients undergoing resection with documented PET scan (Quality Indicator 10)

SITE	1	2	3	4	5	6	7	8	TOTAL
Numerator	27	44	48	26	32	10	12	9	208
Denominator	30	48	51	27	42	21	12	15	246
Meeting indicator (crude)	90%	92%	94%	96%	76%	48%	100%	60%	85%
Meeting indicator (risk-adjusted)	88%	94%	91%	92%	80%	50%	94%	61%	-
Data completeness	100%	100%	100%	100%	98%	100%	100%	100%	100%

Note: Surgical resection includes pneumonectomy, lobectomy, segmentectomy and wedge resection

Figure 13 Proportion of patients undergoing resection with documented PET scan (Quality Indicator 10)



PET scanning prior to curative treatment/surgical resection is recognised as a standard of care for NSCLC and SCLC. The availability of a PET scan prior to resection has the potential to allow more appropriate selection of patients for surgical resection, and neoadjuvant and adjuvant therapy.

EFFECTIVE HEALTH CARE

The extent to which improvements in health care are attained, using available evidence-based healthcare measures

Table 11 Proportion of patients with NSCLC (clinical stage IIIB and IV) who have ECOG (0–1) who have commenced chemotherapy (Quality Indicator 20)

SITE	1	2	3	4	5	6	7	8	TOTAL
Numerator	13	24	11	2	5	23	16	7	101
Denominator	31	40	18	4	7	25	27	8	160
Meeting indicator (crude)	42%	60%	61%	50%	71%	92%	59%	88%	63%
Meeting indicator (risk-adjusted)	44%	59%	60%	52%	69%	90%	59%	89%	-
Data completeness	100%	95%	100%	100%	100%	100%	100%	100%	99%

Figure 14 Proportion of patients with NSCLC (clinical stage IIIB and IV) who have ECOG (0–1) who have commenced chemotherapy (Quality Indicator 20)

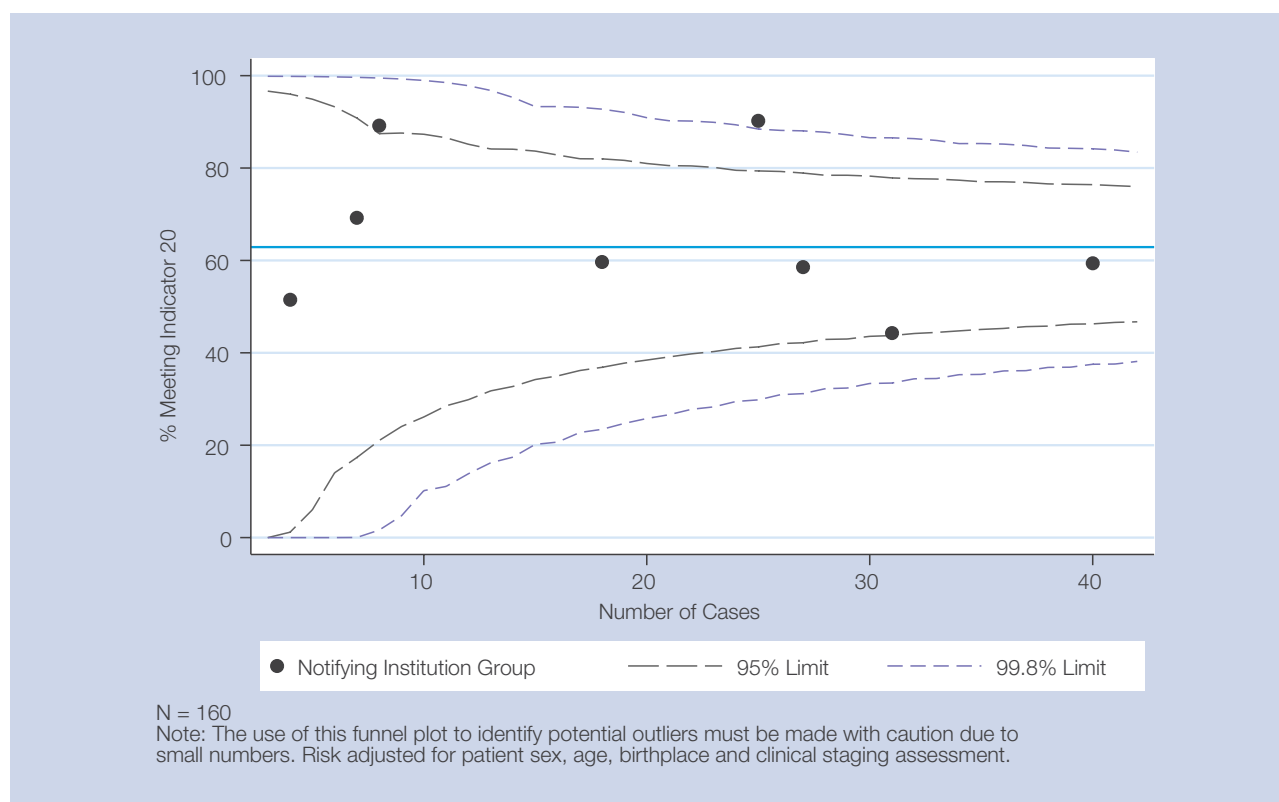
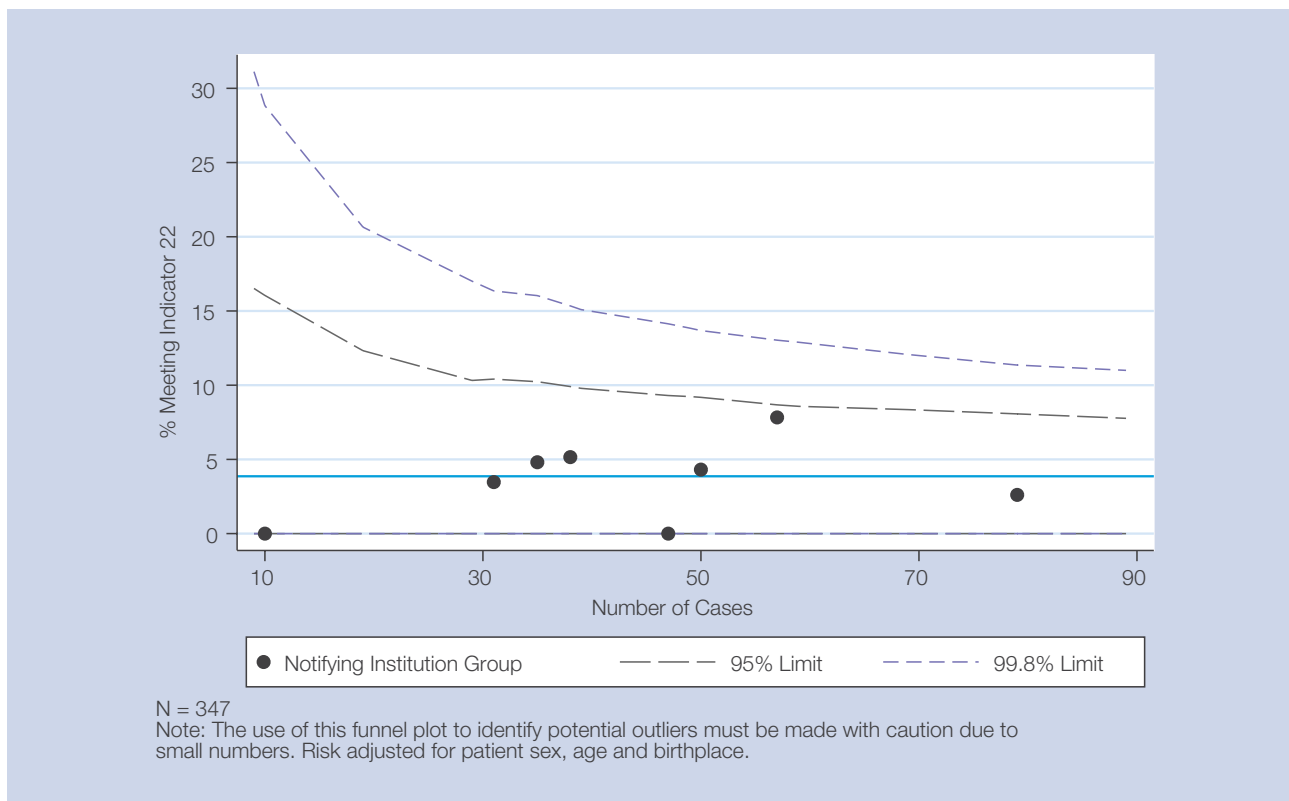


Table 12 Proportion of patients with NSCLC & SCLC where time from chemotherapy start date to death is within 30 days (Quality Indicator 22)

SITE	1	2	3	4	5	6	7	8	TOTAL
Numerator	1	2	2	0	2	5	0	2	14
Denominator	31	79	50	10	35	57	47	38	347
Meeting indicator (crude)	3%	3%	4%	0%	6%	9%	0%	5%	4%
Meeting indicator (risk-adjusted)	3%	3%	4%	0%	5%	8%	0%	5%	-
Data completeness	97%	99%	100%	100%	97%	100%	100%	97%	99%

Figure 15 Proportion of patients with NSCLC & SCLC where time from chemotherapy start date to death is within 30 days (Quality Indicator 22)



PATIENT-CENTRED HEALTH CARE

Providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions.

Table 13 Proportion of patients with screening for supportive care documented (Quality Indicator 5)

SITE	1	2	3	4	5	6	7	8	TOTAL
Numerator	27	72	1	1	21	1	40	36	199
Denominator	123	180	139	39	102	78	109	76	846
Meeting indicator (crude)	22%	40%	1%	3%	21%	1%	37%	47%	24%
Meeting indicator (risk-adjusted)	23%	38%	1%	3%	23%	1%	32%	50%	-
Data completeness	100%	98%	95%	100%	95%	100%	100%	100%	98%

Figure 16 Proportion of patients with screening for supportive care documented (Quality Indicator 5)

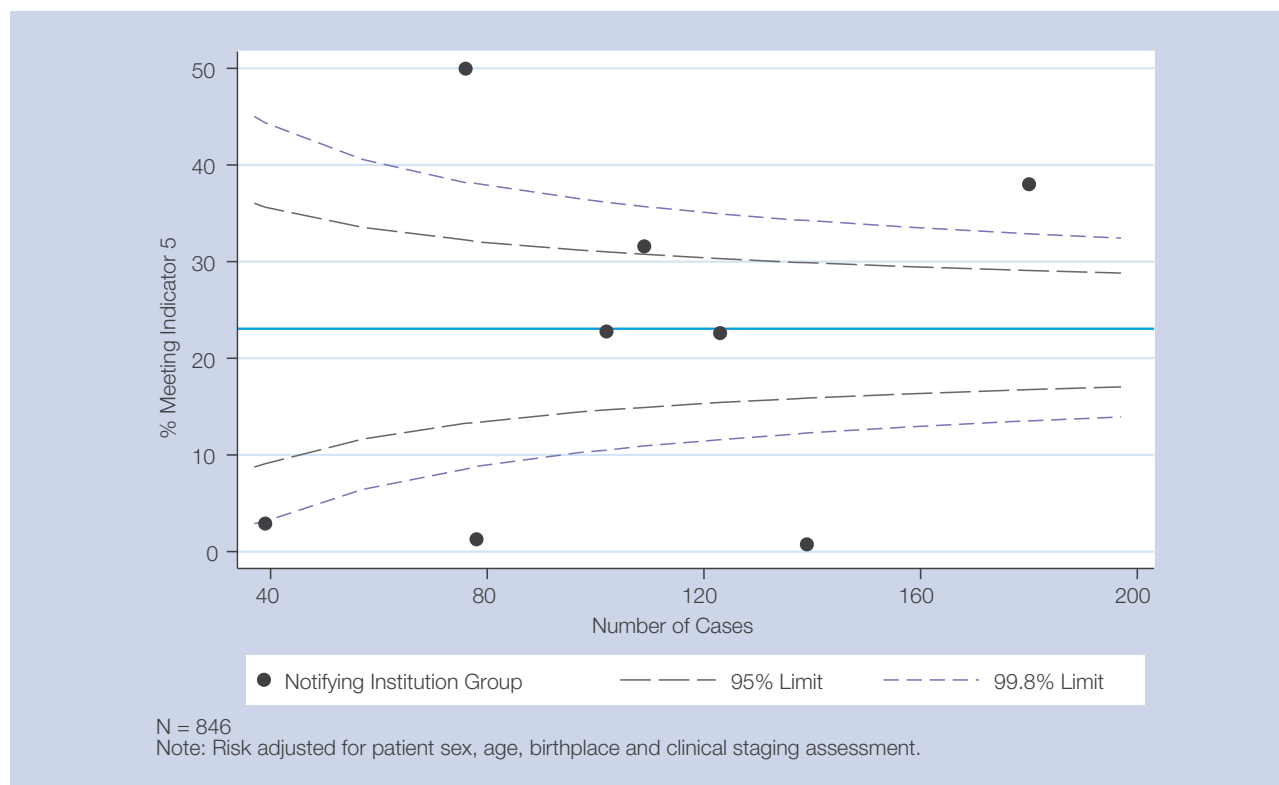
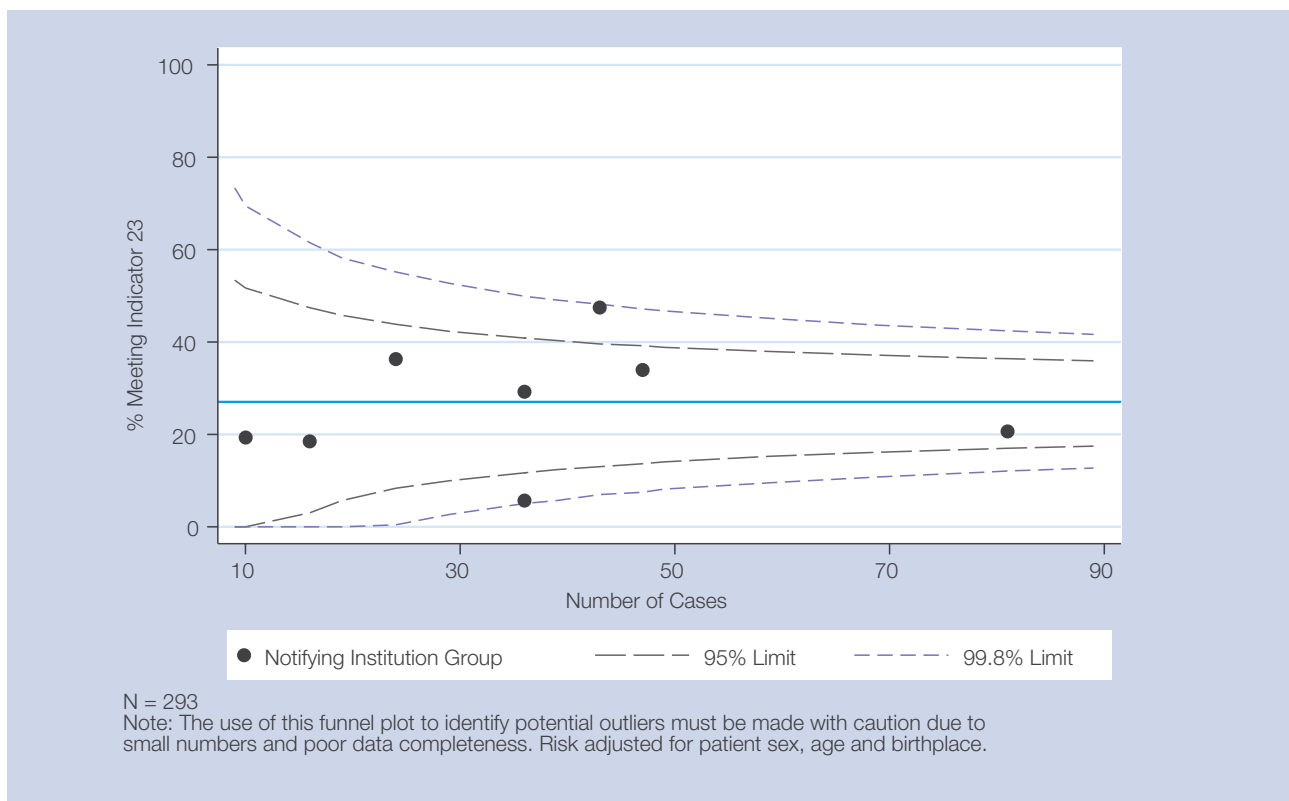


Table 14 Proportion of patients with NSCLC (stage IV) referred to palliative care within 8 weeks of diagnosis (Quality Indicator 23)

SITE	1	2	3	4	5	6	7	8	TOTAL
Numerator	11	16	15	2	10	2	21	3	80
Denominator	36	81	47	10	24	36	43	16	293
Meeting indicator (crude)	31%	20%	32%	20%	42%	6%	49%	19%	27%
Meeting indicator (risk-adjusted)	29%	21%	34%	19%	36%	6%	47%	19%	-
Data completeness	53%	28%	43%	20%	54%	8%	67%	25%	39%

Figure 17 Proportion of patients with NSCLC (stage IV) referred to palliative care within 8 weeks of diagnosis (Quality Indicator 23)



TIMELY HEALTH CARE

Providing care within accepted time limits, after recognising the need for care. This includes the time interval to being seen by a doctor, and the time interval between identifying a need for specific tests and treatments and actually receiving the services.

Table 15 Proportion of patients where referral to diagnosis date is within 28 days (Quality Indicator 1)

SITE	1	2	3	4	5	6	7	8	TOTAL
Numerator	42	76	69	12	41	61	86	27	414
Denominator	61	130	107	22	49	63	105	34	571
Meeting indicator (crude)	69%	58%	64%	55%	84%	97%	82%	79%	73%
Meeting indicator (risk-adjusted)	70%	56%	68%	62%	84%	95%	78%	82%	-
Data completeness	50%	72%	77%	56%	48%	81%	96%	45%	67%

Note: Referral is correspondence from a primary care provider (usually GP) or specialist requesting further investigation of suspected lung cancer

Figure 18 Proportion of patients where referral to diagnosis date is ≤ 28 days (Quality Indicator 1)

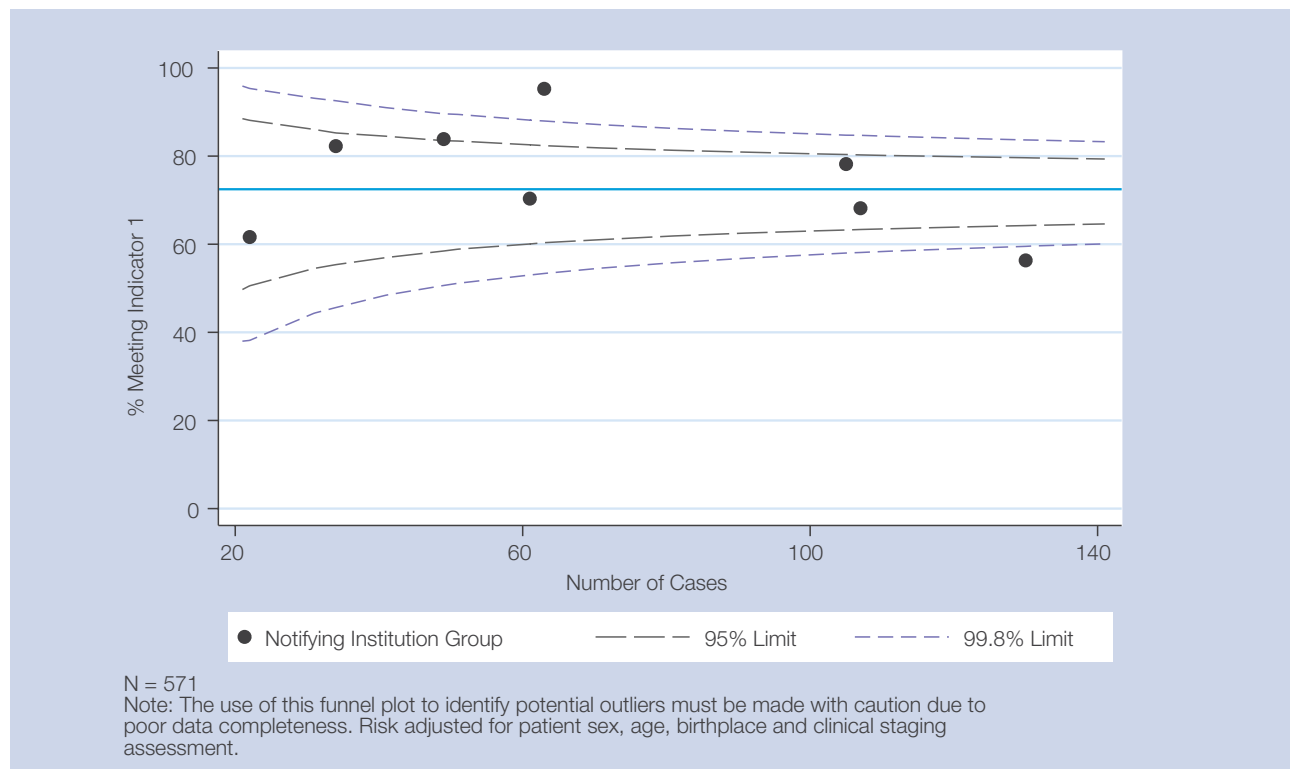
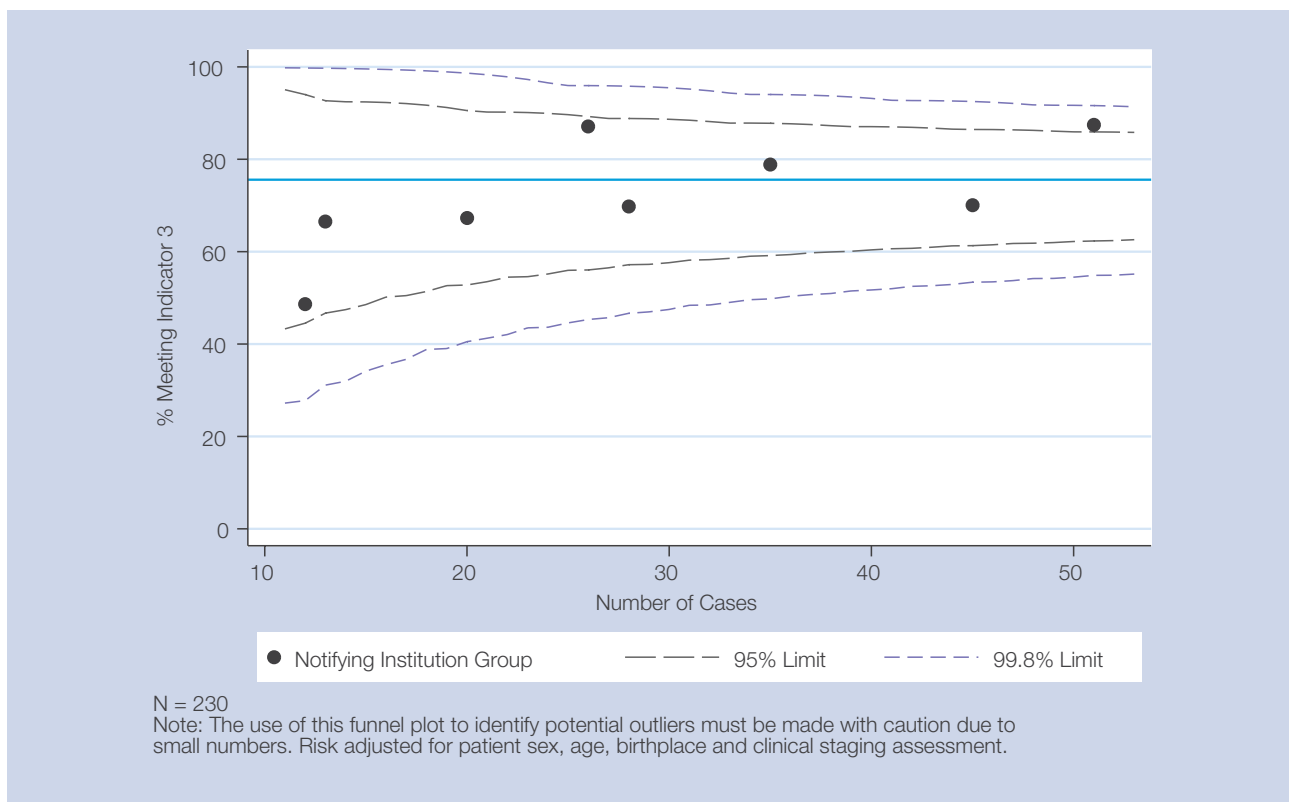


Table 16 Proportion of patients with NSCLC where time from diagnosis to surgical resection is within 14 days (Quality Indicator 3)

SITE	1	2	3	4	5	6	7	8	TOTAL
Numerator	20	31	44	24	28	13	6	8	174
Denominator	28	45	51	26	35	20	12	13	230
Meeting indicator (crude)	71%	69%	86%	92%	80%	65%	50%	62%	76%
Meeting indicator (risk-adjusted)	70%	70%	87%	87%	79%	67%	49%	67%	-
Data completeness	93%	98%	100%	100%	90%	100%	100%	100%	97%

Note: Surgical resection includes pneumonectomy, lobectomy, segmentectomy and wedge resection

Figure 19 Proportion of patients with NSCLC where time from diagnosis to surgical resection is within 14 days (Quality Indicator 3)



EFFICIENT HEALTH CARE

Optimal use of available resources to yield maximum health benefits.

Table 17 Proportion of patients with presentation at a lung cancer multidisciplinary meeting (MDM) documented (Quality Indicator11)

SITE	1	2	3	4	5	6	7	8	TOTAL
Numerator	80	114	103	24	9	20	77	32	459
Denominator	123	180	139	39	102	78	109	76	846
Meeting indicator (crude)	65%	63%	74%	62%	9%	26%	71%	42%	54%
Meeting indicator (risk-adjusted)	64%	64%	66%	53%	11%	27%	68%	44%	-
Data completeness	99%	99%	91%	100%	48%	71%	100%	99%	89%

Figure 20 Proportion of patients with presentation at a lung cancer multidisciplinary meeting (MDM) documented (Quality Indicator11)

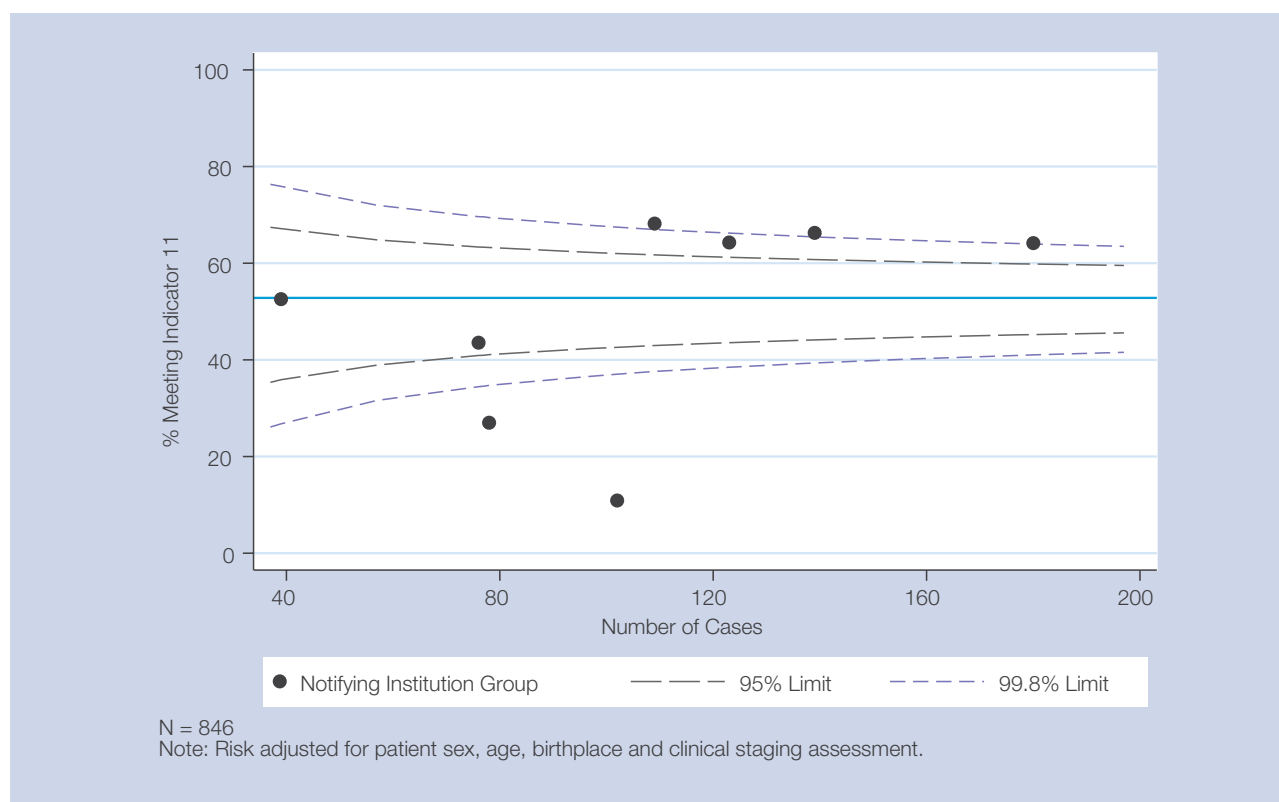
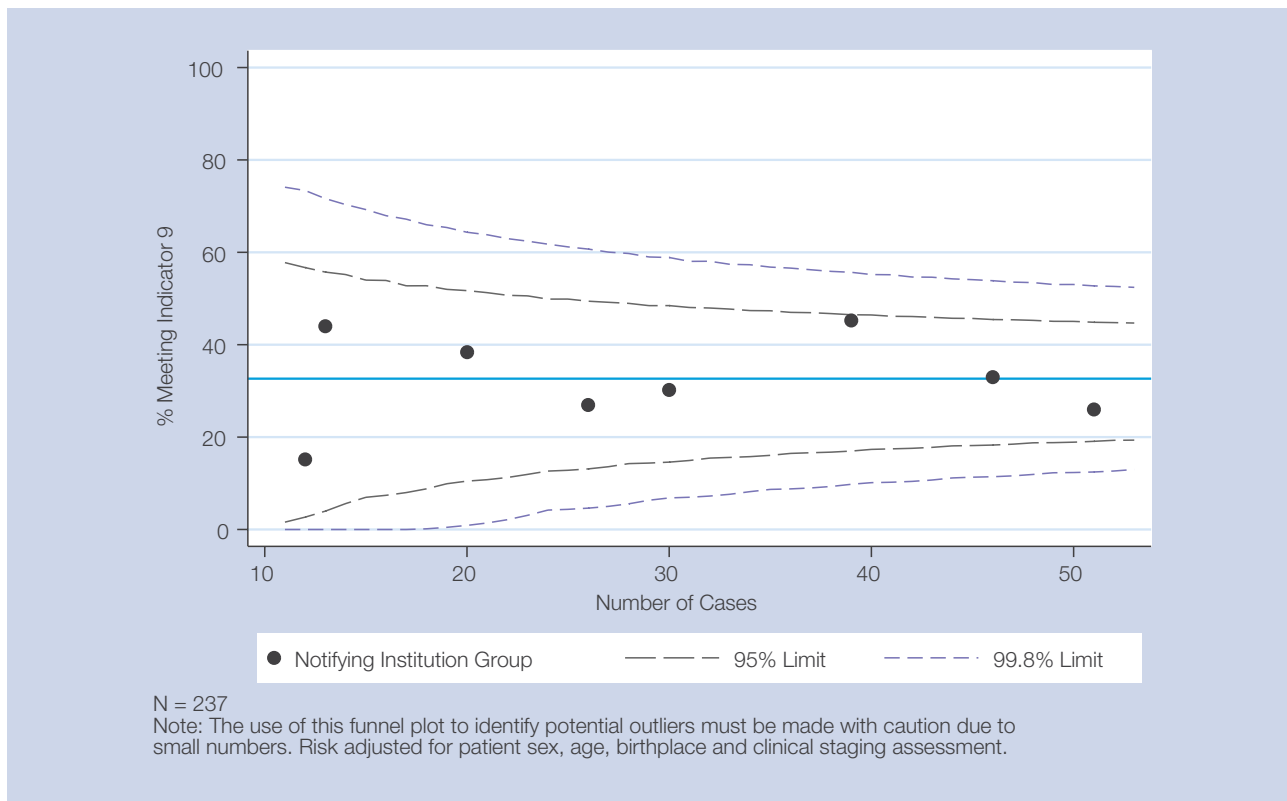


Table 18 Proportion of patients with NSCLC who have undergone a surgical resection and clinical stage (cTN) agrees with pathological stage (pTN) (Quality Indicator 9)

SITE	1	2	3	4	5	6	7	8	TOTAL
Numerator	9	13	18	9	10	8	2	4	73
Denominator	30	46	51	26	39	20	12	13	237
Meeting indicator (crude)	30%	28%	35%	35%	26%	40%	17%	31%	31%
Meeting indicator (risk-adjusted)	30%	33%	26%	27%	45%	38%	15%	44%	-
Data completeness	100%	100%	100%	100%	100%	100%	100%	100%	100%

Note: Surgical resection includes pneumonectomy, lobectomy, segmentectomy and wedge resection

Figure 21 Proportion of patients with NSCLC who have undergone a surgical resection and clinical stage (cTN) agrees with pathological stage (pTN) (Quality Indicator 9)



EQUITABLE HEALTH CARE

Equal distribution of healthcare and its benefits, regardless of gender, ethnicity, geographic location or socio-economic status.

Figure 22 VLCR 2015 Referral to diagnosis by institution type

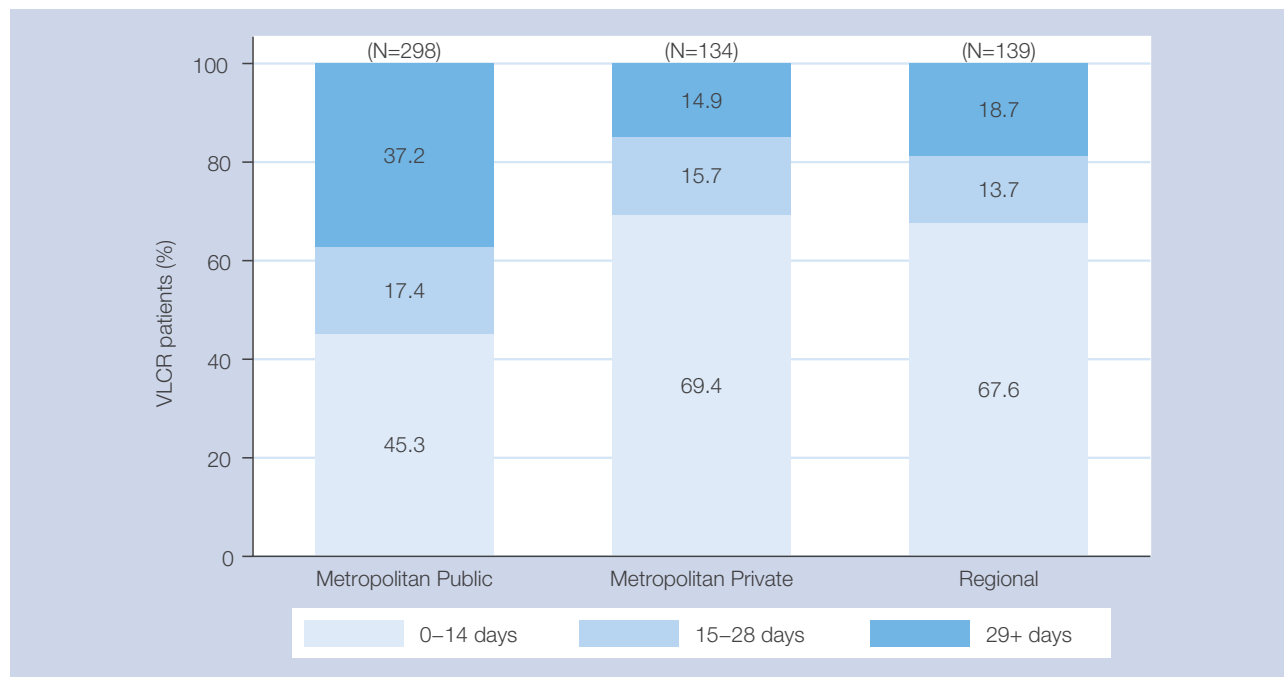
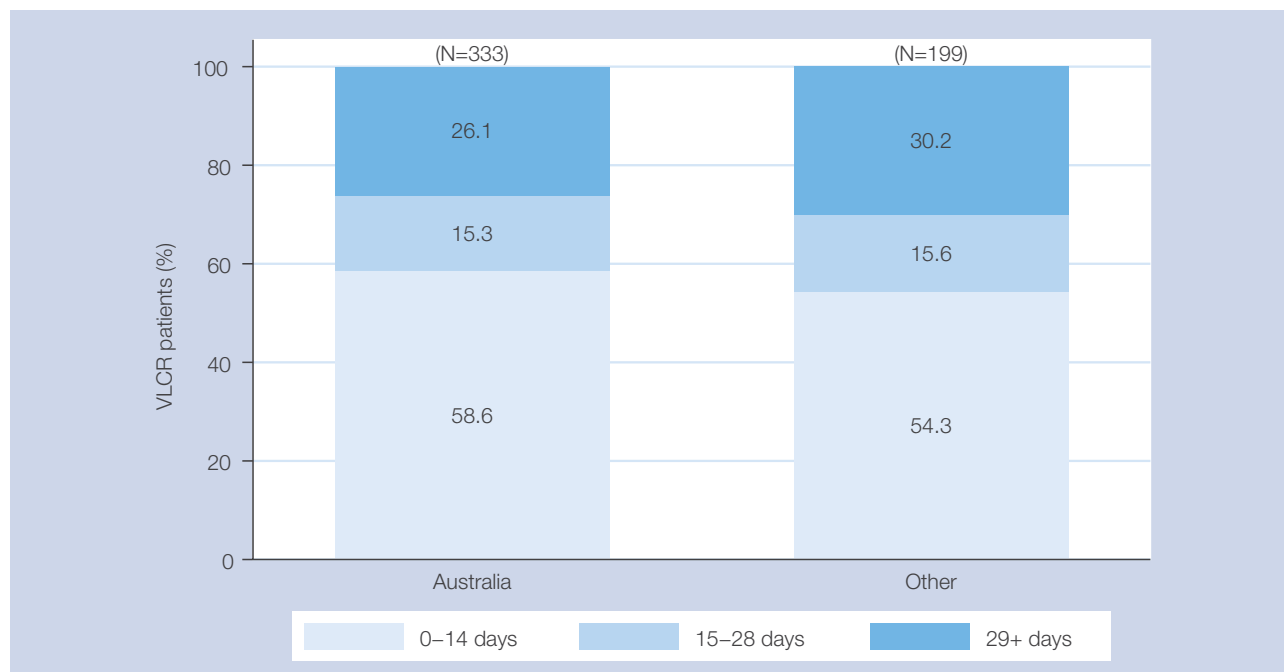


Figure 23 VLCR 2015 Referral to diagnosis by birthplace



Metropolitan Public hospitals had a lower proportion of patients achieving rapid diagnosis (within 14 days from referral) and higher proportion of patients with delayed diagnosis (more than 28 days following referral) compared to Metropolitan Private and Regional hospitals *Figure 22*. Timeliness of diagnosis was similar for Australian born and non-Australian born patients, more than half were diagnosed within 14 days from referral *Figure 23*.

Figure 24 VLCR 2015 Diagnosis to resection by institution type

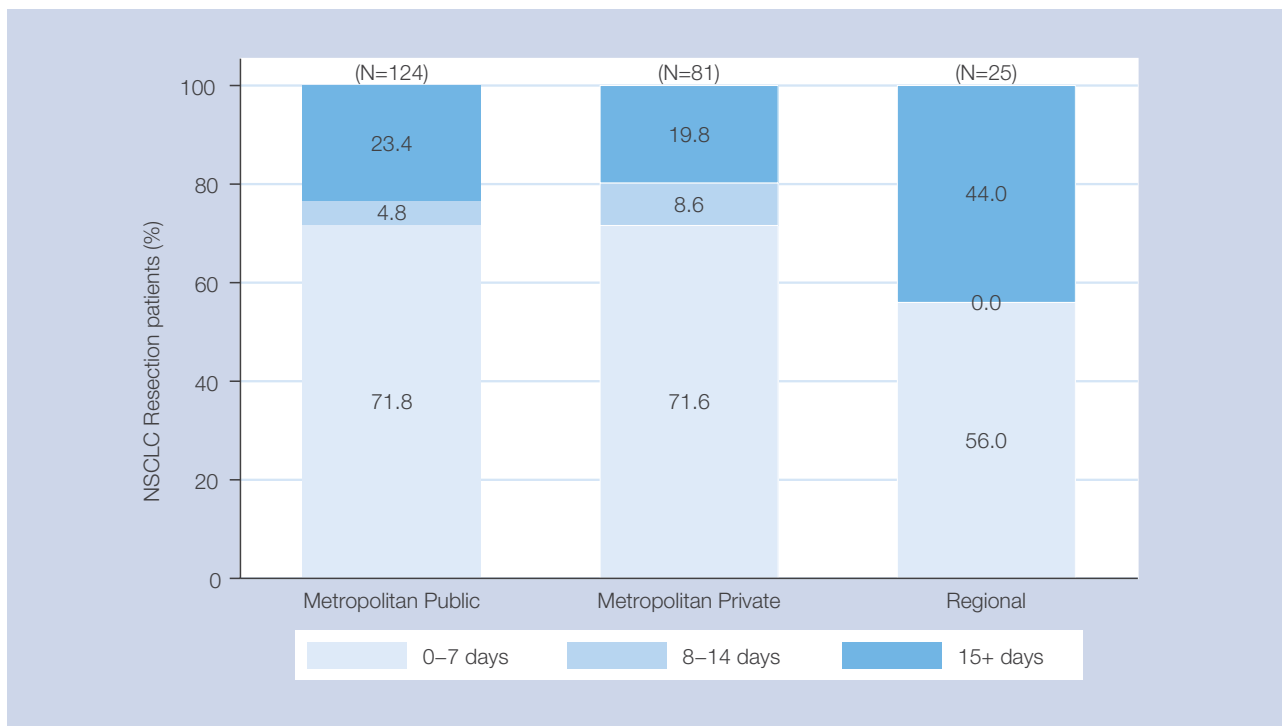
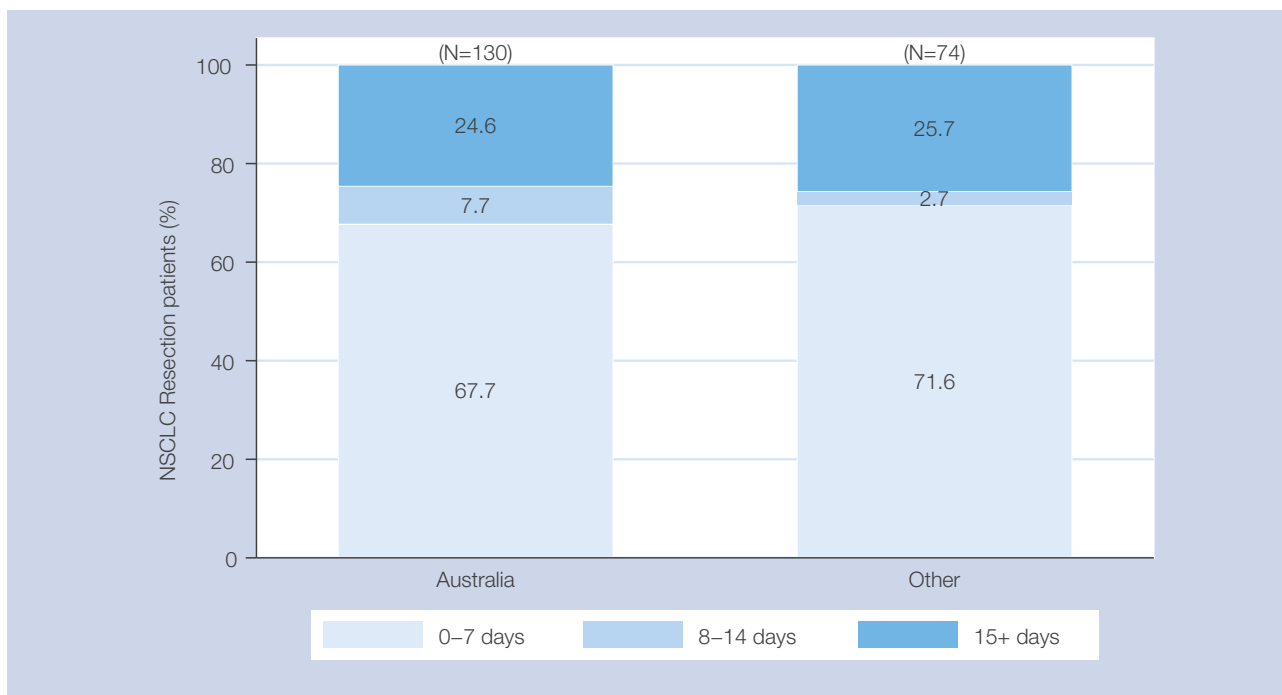


Figure 25 VLCR 2015 Diagnosis to resection by birthplace



Regional hospitals had a lower proportion of subjects undergoing resection within 14 days from the date of diagnosis compared to Metropolitan hospitals (56 % vs 72%) *Figure 24*. However, little difference was found when comparing Australian born and non-Australian born patients; 75.4% of Australian born and 74.3% of non-Australian born patients underwent surgical resection within 14 days from the date of diagnosis *Figure 25*.

Appendices

Appendix A: VLCR governance

The governance of VLCR was established to meet the standards outlined within the operating principles by the Australian Commission for Safety and Quality in Healthcare.

The Registry is governed by a Steering Committee, which is comprised of the following members: consumer representative (1), thoracic physicians (3), thoracic surgeon (1), radiation oncologists (2), medical oncologists (2), palliative care physician (1), general practice doctor (1), cancer nurse (1), epidemiologists (3), a basic scientist (1), representatives from health departments in bioinformatics (1), tissue biobank (1), health department administration (1) and from the state cancer registry (1).

The Management Committee is responsible for managing day-to-day aspects of the clinical register. Data quality measures are reported regularly to the Management Committee.



Appendix B: Steering Committee Membership

Name	Organisation and Title
Professor David Ashley	Director of Medical Oncology, Barwon Health.
Professor David Ball	Deputy Director, Radiation Oncology & Cancer Imaging, Chair, Lung Service, Peter MacCallum Cancer Centre.
Dr Peter Briggs	Clinical Director SMICS.
Shirley Carvosso	Consumer Representative.
Dr Matthew Conron	Director, Department Respiratory and Sleep Medicine, St Vincent's Melbourne.
Mary Duffy	Nurse Coordinator: Lung Services Peter MacCallum Cancer Centre, Melbourne.
Associate Professor Sue Evans	Head, Clinical Registry Unit and Director, CRE in Patient Safety, Monash University.
Helen Farrugia	Director, Victorian Cancer Registry, Cancer Council Victoria.
Associate Professor Vinod Ganju	Medical Oncologist and Clinical Haematologist, Peninsula Oncology Centre.
Professor Louis Irving	Director, Respiratory and Sleep Medicine, Royal Melbourne Hospital.
Associate Professor David Langton	Respiratory & Sleep Physician, Frankston Hospital.
Professor Michael MacManus	Associate Research Director, Department of Radiation Oncology, Peter MacCallum Cancer centre, Melbourne.
Professor John McNeil	Head of School of Public Health & Preventive Medicine, Monash University.
Associate Professor Jeremy Millar	Director of Radiation Oncology at Alfred Health.
Associate Professor Paul Mitchell	Director, North-Eastern Melbourne Integrated Cancer Service, President, Australasian Lung Cancer Trials Group, Olivia Newton-John Cancer and Wellness Centre.
Professor Jennifer Philip	Co-Deputy Director, Centre for Palliative Care, St Vincent's Hospital, Melbourne.
Associate Professor Gary Richardson	Director of Oncology Clinics Victoria, Director of Cabrini Academic Haematology & Oncology Services.
Dr Megan Robertson	Executive Director of Research, Epworth HealthCare.
Associate Professor Ben Solomon	Medical Oncologist, Head Lung Cancer Medical Oncology Service, Peter MacCallum Cancer Centre.
Associate Professor Rob Stirling	Coordinating Principal Investigator and Steering Group Chairman, Victorian Lung Cancer Registry. Consultant Physician, Department of Allergy Immunology & Respiratory Medicine, The Alfred Hospital.
Maureen Turner	Chief Executive Officer, BioGrid Australia.
Associate Professor Gavin Wright	Director of Surgical Oncology, St Vincent's Hospital Melbourne.
Professor John Zalcborg	Tony Charlton Chair of Oncology, Alfred Health. Head, Cancer Research Program, School of Public Health and Preventive Medicine, Monash University.

Appendix C: VLCR escalation policy

The Victorian Lung Cancer Registry (VLCR) is responsible for collection and analysis of treatment and outcome data. Outcome data routinely reported by the Registry includes treatment, time to treatment and mortality. With this activity comes the responsibility to act upon outliers identified by the Registry. An outlier escalation policy has been developed, in line with other Monash University clinical registries, to ensure that if any participating sites are providing sub-optimal care they may be identified and strategies are put in place to prevent patient harm.

In identifying an outlier, the Registry should ensure that the participating site has access to the data that has contributed to the outlier for the period in question. Investigation methodology at the participating site may include reviews of medical records, service models, care processes and/or staffing, and would be expected to be undertaken by clinicians, quality/clinical governance staff and operational management staff.

Depending on the indicator, the process of investigation and escalation of a potential outlier may commence after a single identification, or after a potential outlier has persisted for two reporting periods. Should a potential outlier(s) be identified, a second data analyst should verify the presence of an outlier. Initial registry investigation of a potential outlier includes: i) Checking of data integrity for major errors – data validation ii) Checking of data for major shifts in demographic and case mix for variables not accounted for in the model (i.e. risk-adjustment issues).

The VLCR response to identified outliers includes a three-stage graded response system with escalation to the next stage if an alert has occurred during the previous stage.

The **Level 1** alert or “warning” trigger is set to flag at a statistically significant change from the benchmark of two standard deviations from the mean. If a Level 1 alert is reached data are checked for accuracy and a confidential data analysis report is provided to the principal investigator of the participating site. If ‘outlier status’ is deemed by the site principal investigator or the VLCR Steering Committee not to be a data quality issue, the Medical Director or Head of Unit can be notified.

A **Level 2** alert or “investigation” trigger is set at three standard deviations from the mean. If a Level 2 is reached then the following processes are initiated under direction of the VLCR Steering Committee:

1. Data will again be checked for major errors e.g. validate against hospital records and devices, ensure data entry are correct.
2. Data will be checked for major shifts in that site’s demographic and case mix. E.g. compare age, sex and comorbidity profile.

3. Assess whether there are case mix factors peculiar to this site, explaining the observed variations.

Following this review, confidential communication to the relevant site principal investigator will be provided with results of preliminary analysis and an explanatory report. If an outlier is deemed by the site principal investigator or the VLCR Steering Committee not to be a data quality issue, contact will be made with the Executive Medical Director or the Chairman of the relevant Ethics Committee. This report will also be made available to the Head of Unit or Medical Director. Should this investigation not produce a suitable explanation for an anomaly, investigation will proceed to Level 3.

A **Level 3** alert is flagged if the Level 2 alert persists for more than two consecutive quarters or as above. As with a Level 2 flag, the aim of this stage is to identify and exclude common factors that may lead to a false alarm. A suggested action plan: All of Stage 2 is undertaken (if not already completed) and check for data analysis/coding errors, and if necessary, extract raw data a second time and conduct an independent analysis. Undertake a sensitivity analysis using external (clinical) benchmarks, identify if there have been significant changes in the recalibrated model(s). Should this investigation not provide a suitable explanation for the alert signal(s) a peer review process and audit will be undertaken in collaboration with the institution

The Steering Committee will recommend targeted investigation focusing on areas which are likely to be helpful including, but not limited to the following issues:

Patient factors: Is there significant variation in case mix; has the case mix shifted; or referral patterns changed?

Structure and resource availability: Has there been a change in data collection practices e.g. personnel changes, IT software/hardware changes, data submission; have clinical services been substantially altered e.g. increased workload; has there been a change in funding; has there been a change in resources or in clinical services? Is there an internal clinical audit process or do these internal audit reports highlight areas of interest?

Within a one month period, the Director of Medical Services or Head of Unit will be notified with a written report of the findings of this review. Recommendations may be made e.g. improvement to resources, staffing, training, clinical audit, peer review. Issues will be raised with the Chief Executive Officer if the committee is not satisfied with explanation for persistent outlier status in regard to mortality and if actions are not initiated.

Appendix D: Clinical Quality Indicators

Numerator: the number of patients that satisfy the condition defined in the denominator and data value used to calculate the indicator have been verified as correct in VLCR.

Denominator: the number of patients diagnosed with primary lung cancer in 2015 who meet the indicator definition and have been entered into the VLCR

No.	Numerator	Denominator
Timeliness Indicators:		
1	Number of patients where time from referral date to diagnosis is ≤ 28 days	Number of patients in Registry with a referral date available
2	Number of patients where time from diagnosis date to first treatment date (any intent) is ≤ 14 days	Number of patients in Registry receiving anti-cancer treatment with a defined date
3	Number of patients with NSCLC where time from diagnosis date to surgical resection date is ≤ 14 days	Number of NSCLC patients in Registry undergoing surgical resection with defined date.
4	Number of patients where time from referral date to first treatment (any intent) is ≤ 42 days	Number of patients in Registry undergoing anti-cancer treatment with referral date and treatment date available.
Documentation in Medical Records Indicators		
5	Number of patients with documented screening for supportive care	Number of patients in Registry
6	Number of patients with documented ECOG status	Number of patients in Registry
7	Number patients with clearly documented cTNM staging	Number of patients with NSCLC in Registry
8	Number of patients with NSCLC undergoing surgical resection with clearly documented pTN	Number of patients with NSCLC who have undergone surgical resection
9	Number of NSCLC patients undergoing surgical resection where cTN agrees with pTN	Number of patients with NSCLC undergoing surgical resection with cTN and pTN available
10	Number of patients undergoing resection with clearly documented PET scan	Number of patients undergoing resection
11	Number of patients with documented presentation at a lung MDM	Number of patients in Registry
Tissue Diagnosis Indicator		
12	Number of patients with confirmed tissue diagnosis (malignant cytology or histology)	Number of patients in Registry
Surgical Indicators		
13	Number of patients with NSCLC who have had surgical resection	Number of patients with NSCLC
14	Number of patients with NSCLC (clinical stage I or II) undergoing resection	Number of patients with NSCLC (clinical stage I or II)
15	Number of patients with NSCLC (clinical stage I or II) undergoing lobectomy	Number of patients with NSCLC (clinical stage I or II) who have undergone surgical resection
16	Number of patients with NSCLC (clinical stage I or II) and VATS resection	Number of patients with NSCLC (clinical stage I or II) who have undergone surgical resection
17	Number of patients with NSCLC (clinical stage I or II) and resection with ≥ 5 lymph nodes dissected	Number of patients with NSCLC (clinical stage I or II) who have undergone surgical resection
18	Number of patients with NSCLC who have had a surgical resection and died within 30 days of surgery.	Number of patients with NSCLC who have undergone surgical resection

No.	Numerator	Denominator
Anti-Cancer Treatment Indicators		
19	Number of patients receiving anti-cancer treatment (surgery, radiotherapy, chemotherapy or biological therapy)	Number of patients in Registry
20	Number of patients with NSCLC (stage IIIb or IV) who have ECOG (0–1) and have commenced chemotherapy	Number of patients with NSCLC (stage IIIb and IV) + ECOG (0–1)
21	Number of patients NSCLC (pathological stage II) receiving platinum based chemotherapy + complete resection	Number of patients with NSCLC (pathological stage II) who have undergone a surgical resection
22	Number of patients with lung cancer where time from chemotherapy start date to death date is ≤ 30 days	Number of patients receiving chemotherapy
Palliative care Indicator		
23	Number of patients with NSCLC (stage IV) referred to palliative care within 8 weeks of diagnosis	Number of patients with NSCLC (stage IV)

Appendix E: Case Ascertainment and Data Completeness

Completeness and accuracy of recruitment of the eligible population has been assessed on a scheduled basis by comparing data from the clinical registry with other data sources such as the Victorian Cancer Registry, the Victorian Admitted Episode Data, and hospital clinical record data.

Case ascertainment for VLCR will occur via notification by participating site Health Information Systems of hospital discharges confirming ICD 10 coding identifying lung cancer as the principal reason for admission. Prevalence cases are discarded and incident cases are reviewed for inclusion and exclusion criteria. All patients over 18 years with a primary lung cancer, that is not a carcinoid or mesothelioma, will be eligible for inclusion. Diagnoses may be confirmed by pathology or on a clinical basis using ICD-10 coding (version 2016) C34.0-34.3, C34.8-34.9, R91-85.2. Patients with secondary cancer of the lung and those diagnosed prior to governance approval for a participating site, will be ineligible. Newly diagnosed patients will be sent explanatory statements and informed of the opt-out consent strategy. If no opt-out is received within two weeks, data collection for the patient will proceed.

Appendix F: References

1. Australian Institute of Health and Welfare, 2016. AIHW [accessed February, 2017]
2. Cancer Council Victoria. Cancer in Victoria Statistics and trends, 2015
3. American Cancer Society, "Lung Cancer (Non-Small Cell)", last updated May 2016, <http://www.cancer.org/cancer/lungcancer-non-smallcell/detailedguide/non-small-cell-lung-cancer-survival-rates>
4. Australian Institute of Health and Welfare & Cancer Australia, Cancer in Aboriginal and Torres Strait Islander peoples of Australia: an overview (Canberra: AIHW, 2013)
5. Evans SM, Earnest A, Bower W, Senthuren M, McLaughlin P and Stirling R. Timeliness of lung cancer care in Victoria; a retrospective cohort study. *Med J Aust* 2016; 204 (2): 75
6. Department of Health and Human Services, Victorian. Targeting zero, the review of hospital safety and quality assurance in Victoria, 2016 Institute of Medicine (IOM). *Crossing the Quality Chasm: A New Health Care System for the 21st Century*. Washington, D.C. National Academy Press;2001

Appendix G: Registry Publications, Presentations and Seminars

Balancing convenience and outcome in cancer surgery center selection: Patient choice in quality improvement. Stirling RG. *Surgery*. 2017 May;161(5):1465-1466

Defining a standard set of patient-centred outcomes for lung cancer. Mak KS, van Bommel AC, Stowell C, Abraham JL, Baker M, Baldotto CS, Baldwin DR, Borthwick D, Carbone DP, Chen AB, Fox J, Haswell T, Koczywas M, Kozower BD, Mehran RJ, Schramel FM, Senan S, Stirling RG, van Meerbeeck JP, Wouters MW, Peake MD; Lung Cancer Working Group of ICHOM. *Eur Respir J*. 2016 Sep;48(3):852-60

Defining Measures of Quality in Lung Cancer Diagnosis and Staging. Stirling RG, Russell PA, Wright GM. *Ann Thorac Surg*. 2016 Apr;101(4):1628

The Influence of Comorbidity and the Simplified Comorbidity Score on Overall Survival in Non-Small Cell Lung Cancer-A Prospective Cohort Study. Alexander M, Evans SM, Stirling RG, Wolfe R, Officer A, MacManus M, Solomon B, Burbury K, Ball D. *J Thorac Oncol*. 2016 May;11(5):748-57

Timeliness of lung cancer care in Victoria: a retrospective cohort study. Evans SM, Earnest A, Bower W, Senthuren M, McLaughlin P, Stirling R. *Med J Aust*. 2016 Feb 1;204(2):75.e1-9.

Clinical quality registries: engaging effectiveness data for quality improvement. Stirling RG. *Am J Public Health*. 2014 Dec;104(12):e10

The Victorian Lung Cancer Registry pilot: improving the quality of lung cancer care through the use of a disease quality registry. Stirling RG, Evans SM, McLaughlin P, Senthuren M, Millar J, Gooi J, Irving L, Mitchell P, Haydon A, Ruben J, Conron M, Leong T, Watkins N, McNeil JJ. *Lung*. 2014 Oct;192(5):749-58

The Victorian Lung Cancer Summit: reanalysing existing datasets to identify opportunities to improve patient outcomes. Paul Mitchell, Mirela Matthews, Myra McGuinness, Mandy Byrne, Katherine Simons, Rob Stirling, David Ball. VICS 2015

Quality in Lung Cancer Care: The Victorian Lung Cancer Registry Pilot Initial Report. Stirling RG, Evans S, Senthuren M, McLaughlin P, MacLaughlin-Barratt, S and McNeil JJ. VICS 2015.

Quality in lung cancer care: The development of a population-based lung cancer registry - Victorian Lung Cancer Registry Report 2015. Cabrini Research Day 2016. Session 4 – Cancer Best oral presentation.



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