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# VICTORIAN LUNG CANCER REGISTRY

ANNUAL REPORT 2018

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# FOREWORD

It is with great pleasure that I present the Victorian Lung Cancer Registry (VLCR) 2018 Annual Report.

Lung cancer remains a major disease burden in Victoria and requires a complex and multidisciplinary approach to ensure optimal care and outcomes. The evaluation of these complex patterns of care has the capacity to inform and enhance future treatment for Victorian patients.

The VLCR established a collaboration with clinicians, health services, researchers and consumers in 2011, to capture clinical outcomes, and patterns and quality of care delivered to patients diagnosed with lung cancer in Victoria. This 2018 Annual Report includes outcome data from 19 participating health services including 50 hospitals capturing over 80% of all patients newly diagnosed with a primary lung cancer in Victoria, in the 2018 calendar year.

VLCR reports identify significant variation in practice from clinical practice guidelines, significant practice variation between participating institutions and identify multiple potential targets and opportunities for quality improvement in current lung cancer management.

I would like to acknowledge and thank patients who have agreed to participate in the Registry. I would also like 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.

The VLCR is managed by the Department of Epidemiology and Preventive Medicine, Monash University, which manages more than 20 clinical quality registries. 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 Catherine Martin, who have put significant work into this report.

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, MPH, FRACP**  
**Coordinating Principal Investigator, Steering Committee Chairman**  
**Victorian Lung Cancer Registry**



“Lung cancer remains a major disease burden in Victoria and requires a complex and multidisciplinary approach to ensure optimal care and outcomes.”

# EXECUTIVE SUMMARY

The VLCR is a clinical quality registry that collects “real world” observational data from participating health services to benefit patients, and to inform clinicians and other key stakeholders about the quality of care delivered to patients newly diagnosed with lung cancer in Victoria. Over the past decade, clinical quality registries have had considerable success in driving improvements in health outcomes [1-5], with evidence showing they are not only effective in reducing variation and improving health outcomes, but also in reducing health care spending [6].

The VLCR data are based on a number of clinical quality indicators that measure compliance with agreed best practice. The clinical quality indicators included in this report are risk-adjusted and benchmarked to allow health services to measure their performance relative to other participating Victorian health services. Whilst in 2018 the VLCR population capture grew to over 80% of all newly diagnosed cancer cases in Victoria who had at least one in-hospital admission, it is important to note that some indicators reported have low numbers and therefore, must be interpreted with caution.

## KEY FINDINGS IN 2018:

**Patients:** New registrations were 42.5% females and 47.5% males, with a mean age of diagnosis of 70.4 years for females and 69.0 years for males. Current smokers represent 36.5% for new registrations and never smokers 11.6%. Patients born outside Australia represent 41% and those identifying with Aboriginal and Torres Straits Island status were 0.9%.

**Cancer Type:** Non-Small Cell Lung Cancer represented 86.5% and Adenocarcinoma 58.9%.

**Management:** Over 2/3 (69%) of patients were presented to the Multi-Disciplinary Meeting prior to treatment. Active anti-cancer treatment was delivered to 82% of patients and 27% underwent surgical resection, 42% radiotherapy and 49% systemic anti-cancer treatment.

**Surgical resection:** Post-operative mortality remains low (2% mortality within 30 days), and the documentation of preoperative PET scanning prior to lung cancer resection also remains high (92%).

**Chemotherapy treatment:** Provision of chemotherapy to NSCLC patients with advanced disease (IIIb/IV) and good performance status (ECOG <2), was high (78%), but there is variation between health services (60-100%).

**Supportive care screening:** Evidence of screening patients using the Supportive Care Screening Tool and Distress Thermometer remains low (28%), with significant variation between health services (2-53%). This finding should stimulate health services to consider the importance of the indicator and opportunities for improvement to meet best practice guidelines.

**Palliative care:** Palliative care referral is recommended for all patients with stage IV inoperable NSCLC within 8 weeks of diagnosis. In 2018, we report that of the 737 patients who presented with stage IV NSCLC, only 38% had documentation indicating they were referred to palliative care within 8 weeks of diagnosis. There was a wide variation across health services (7-55%).

**Timeliness of care:** Referral to diagnosis within 28 days was recorded for 72% of patients, with wide variation between health services (53-87%). Time from diagnosis to surgical treatment within 14 days was recorded for 62% of patients with NSCLC.

**Timeliness of care by geographical region and SES status:** A higher proportion of regional health service patients had a referral to diagnosis time within 28 days (80.1%) and less delays beyond 42 days (11.5%), compared with metropolitan public health services (69.2% and 18.0% respectively,  $p=0.001$ ). The highest SES (most advantaged) decile had more resections within 14 days (78.8%) and less delays beyond 28 days (13.5%) compared with the lowest (most-disadvantaged) decile (40.6% and 31.3% respectively,  $p=0.03$ ).

**Multidisciplinary meeting (MDM):** Presentation of patients at MDMs was recorded for 69% of patients diagnosed in 2018, with wide variation between institutions (23-90%). This shows a steady improvement in overall performance previously reported by the VLCR (2015, 54% and 2016, 58%, 2017, 65%).

**Survival analysis:** Median survival time for the 2018 cohort was 1.23 years. Kaplan-Meier estimates show 54.6% survival at one year and 26.5% survival 5 years from diagnosis. Survival rates are lower for patients diagnosed after 80 years of age (39.4% vs 55.4% for 70-79 years) and also lower for patients presenting at a later clinical stage (stage I 90.9% and stage IV 34.0%).

**Equity:** The proportion achieving diagnosis within 28 days of referral varied between 69.2% (metropolitan public hospitals) and 80.1% (regional hospitals). Country of birth did not significantly affect timeliness of diagnosis (Australian born 73.2% vs Overseas born 68.9%). Timeliness of resection (<14 days diagnosis to resection) was 50% in regional hospitals and 77.6% in private hospitals.

“It is important to note that the strongest evidence overall on how to genuinely improve quality and safety exists for clinical quality registry and benchmarking systems, which use clinical registry data to compare the performance of providers, to identify best practice and to drive improvements in quality and patient outcomes.”

**ACSQHC, 2019.**

# ANNUAL REPORT 2018

## REGISTRY OVERVIEW AND REPORTING

Lung Cancer remained the fourth most commonly diagnosed cancer in Victoria in 2018 and the leading cause of cancer deaths in both men and women [7]. With very high symptom burden and mortality, lung cancer is the biggest contributor to Australia's overall cancer burden, as calculated by disability adjusted life years [8]. Although overall age-standardised incidence has fallen slightly in Australia, attributable to reduction in tobacco smoking over previous decades, an increasing number of non-smokers (mainly women) are now being diagnosed with lung cancer [9].

The Australian Commission on Safety and Quality in Health Care (ACSQHC) report in 'The State of Patient Safety and Quality in Australian Hospitals 2019' that "it is important to note that the strongest evidence overall on how to genuinely improve quality and safety exists for clinical quality registry and benchmarking systems, which use clinical registry data to compare the performance of providers, to identify best practice and to drive improvements in quality and patient outcomes" [10].

Quality improvement is now a driving force in health care and is an essential aspect of service delivery at all levels. Put simply, quality is everyone's business. If we don't measure quality, it's difficult to know exactly what to improve and whether we have in fact achieved improvement, so efforts to improve systems or processes must be driven by reliable data.

The VLCR is a Clinical Quality Registry (CQR) that aims to assist health services in developing quality improvement initiatives targeting optimal care delivery consistent with accepted clinical practice guidelines. Data collected across multiple health services are used to reports key process and outcome measures in the management of patients with lung cancer. 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. Clinical quality registry benchmark reporting has been demonstrated nationally and internationally to improve quality of care by identifying gaps, facilitating planning and evaluation of change [1, 2, 11].

The VLCR provides two risk-adjusted benchmark reports. The first is an Annual Quality Indicator (QI) Report that includes 21 quality indicators, selected by the VLCR Steering Committee to reflect key measures of care. The QI report includes all patients diagnosed in a single calendar year and it is reviewed and approved by the VLCR Steering Committee, before being forward to participating institutions clinicians, hospital administrators and quality managers.

The second report produced is the publicly available Annual Report that includes selected quality indicators from the 2018 QI report to reflect key domains of care (safe, timely, patient-centred, efficient, evidence-based and equitable care). The VLCR Annual Report also includes aggregated, descriptive data for all patients in the Registry and it includes Kaplan Meier survival curves describing survival after diagnosis (1, 2 and 5-years after diagnosis).

The VLCR is housed at Monash University in the Department of Epidemiology and Preventive Medicine (DEPM), which acts as the custodian of the VLCR. Funding for the Registry comes from government, public and private sources. The 2018 Annual Report is the fourth Annual Public Report produced by the Victorian Lung Cancer Registry.

## DATA COLLECTION

In 2018, 19 health services (over 50 hospitals) participated in the Registry, of which ten are metropolitan public health services; three are metropolitan private health services and six regional health services. This comprised 2,172 eligible and consented new registry patients for 2018, 70 patients (3%) declined consent and were excluded from the registry. The total number of patients registered since 2011 is 8,038.

The data contained in this document were extracted from the Victorian Lung Cancer Registry in November, 2019 for patients diagnosed with primary lung cancer from 1st January to 31st December, 2018. Data are collected from multiple sources, including passive data linkage and manual collection by trained data collectors from patient medical records.

Patients who were diagnosed with lung cancer during the 2018 calendar year may not be captured in this report if they were not admitted to hospital, or data collection for a participating site is incomplete at the time of the data extraction for analysis.

The date of death used in this report was updated by Victoria Births Deaths and Marriages as at July 13th, 2020 (see Appendix G for date of death data collection process).

## REGISTRY GOVERNANCE

The VLCR operates within an NMA ethics approved protocol (HREC/16/Alfred/84) and it is managed by a governance structure [12] which is consistent with the framework developed by the Australian Committee on Safety and Quality in Healthcare (ACSQHC), (see Appendix D).

# REGISTRY METHODOLOGY

Following notification of all new lung cancer cases from participating health services, patients are screened for eligibility by trained data collectors. Inclusion criteria are all new cases of primary lung cancer. Exclusion criteria include: patients who present with secondary lung cancer, mesothelioma, carcinoid cancer, or disease diagnosed before the health service-specified commencement date. Those who have contacted the Registry to opt out are also excluded.

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-out' of the Registry before collection of clinical and personal data commences. Patients have the option to withdraw their consent to participate at any time.

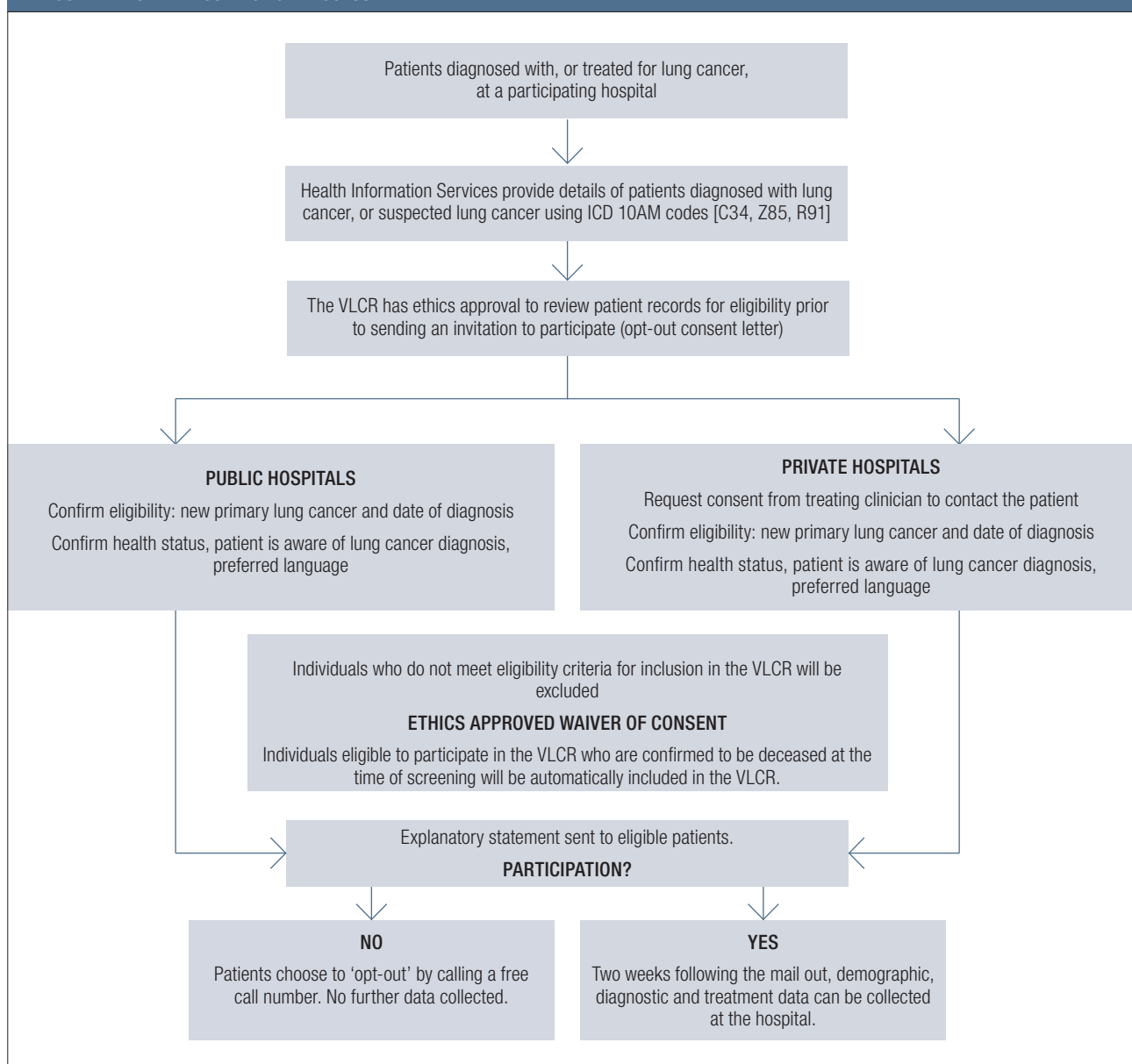
**The VLCR data collection process can be described as follows.**

**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-out consent period. At this point trained data collectors will review medical records to collect key clinical information.

**Stage 3:** Collection of patient reported outcomes at 6 and 12 months post diagnosis will recommence for selected sites in future reports.

FIGURE 1: VLCR DATA COLLECTION PROCESS





# REGISTRY SITE PARTICIPATION

## REGISTRY SITE PARTICIPATION

Figure 2 below shows the total number of participant registrations by year, since the Registry commenced in 2011 (N = 8,380). In 2018, 2,172 new lung cancer cases were captured by the VLCR.

FIGURE 2: CUMULATIVE VLCR REGISTRATIONS 2011–2018

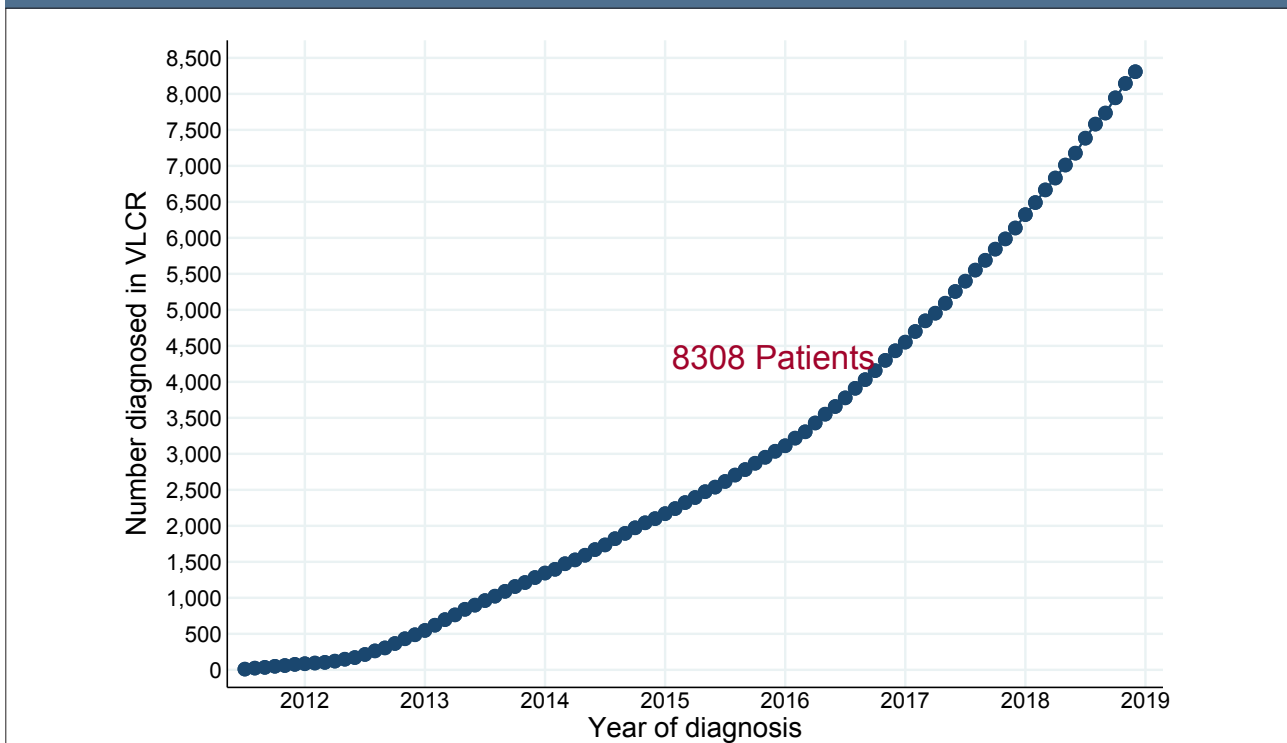
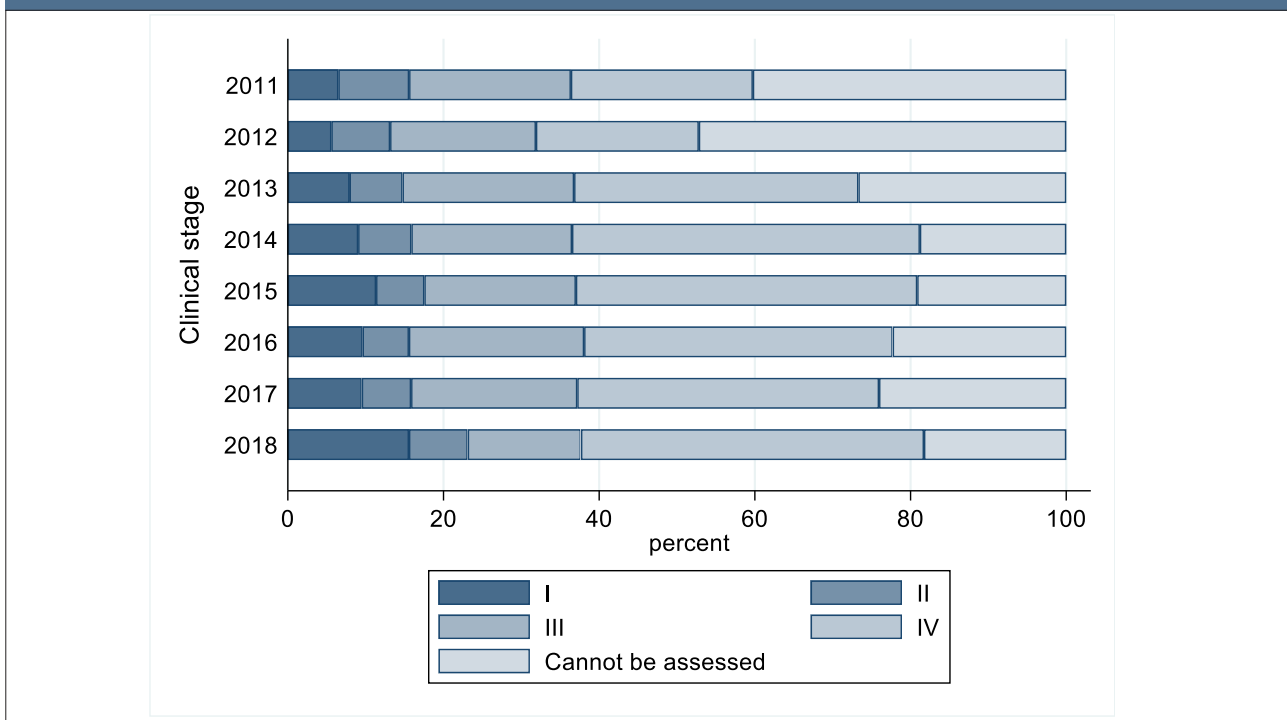


Figure 3 below lists the cumulative patient registrations from 2011–2018 by clinical stage.

FIGURE 3: CUMULATIVE REGISTRATIONS BY CLINICAL STAGE 2011–2018



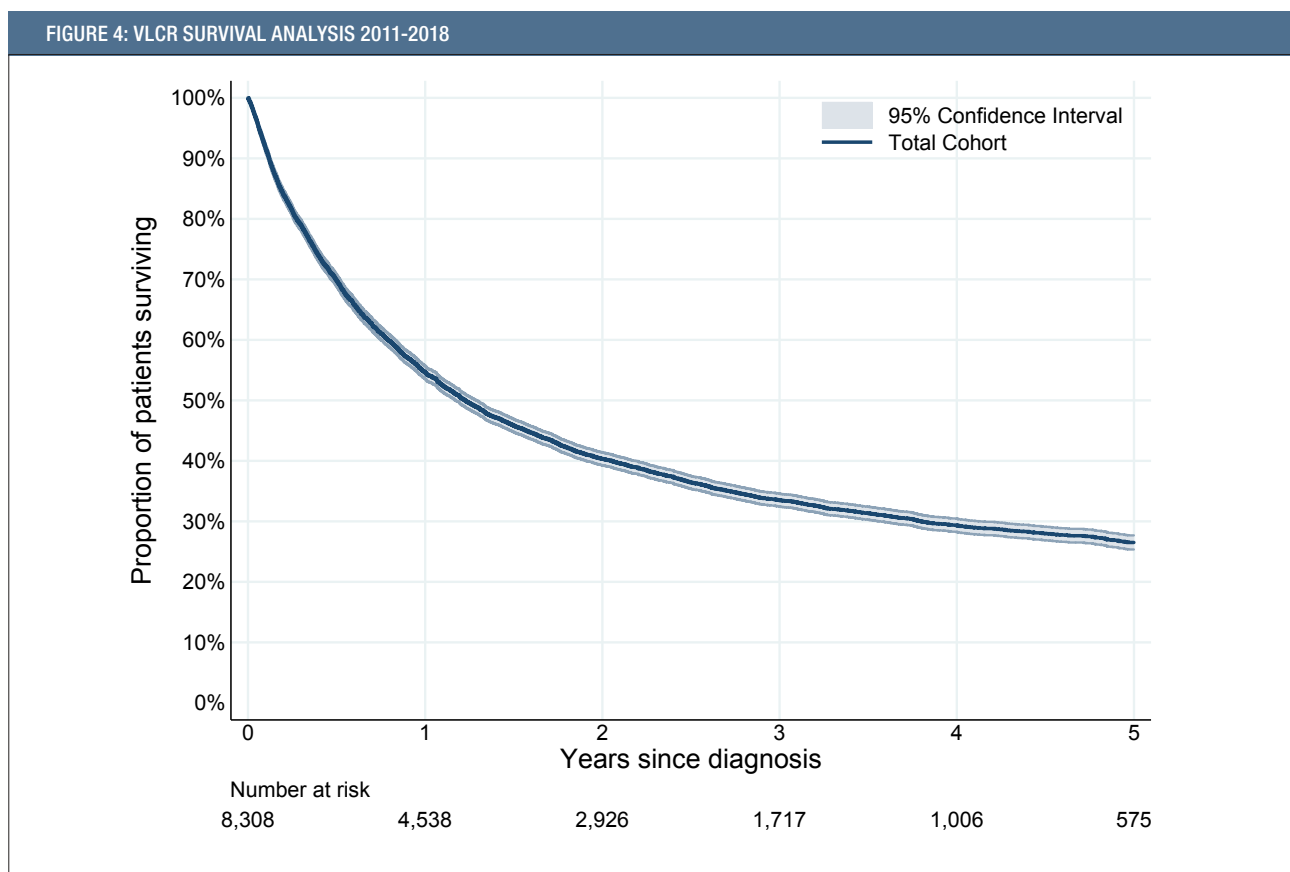
# SURVIVAL ANALYSIS 2011-2018 REGISTRATIONS

Kaplan-Meier estimates of survival using 2011-2018 VLCR registrations are presented in Figure 4 and Table 1. Survival is also stratified by sex, age quartile groups and clinical stage in Figures 4-6. Survival rates are presented at annual time intervals from date of diagnosis with no adjustment for risk factors. The number at risk denotes the number of patients that have been followed up at that particular time point.

Multiple sources of death information were used to confirm a death date for patients. The primary source of death information was from the Victorian Registry of Births, Deaths and Marriages (Vic-BDM) received July 13<sup>th</sup>, 2020. Vic-BDM provided the VLCR with Death Registry data for patients with an exact match on surname, given names and date of birth. Vic-BDM also provided death data for patient “partial matches” where surname and date of birth were matched, but only one given name could be matched.

These partial Vic-BDM matches were used if verified with death data recorded by VLCR via institution Hospital Information Systems (HIS). Those not verified by VLCR HIS information went through a second verification process that involved manual searches via public death notice sources such as the Ryerson Index (death notices in Australian newspapers).

Where no Vic-BDM death date was provided or verified, the VLCR HIS death information was used to further populate the death date field. Appendix G outlines the process described above, including the number of cases at each stage of matching and verification.



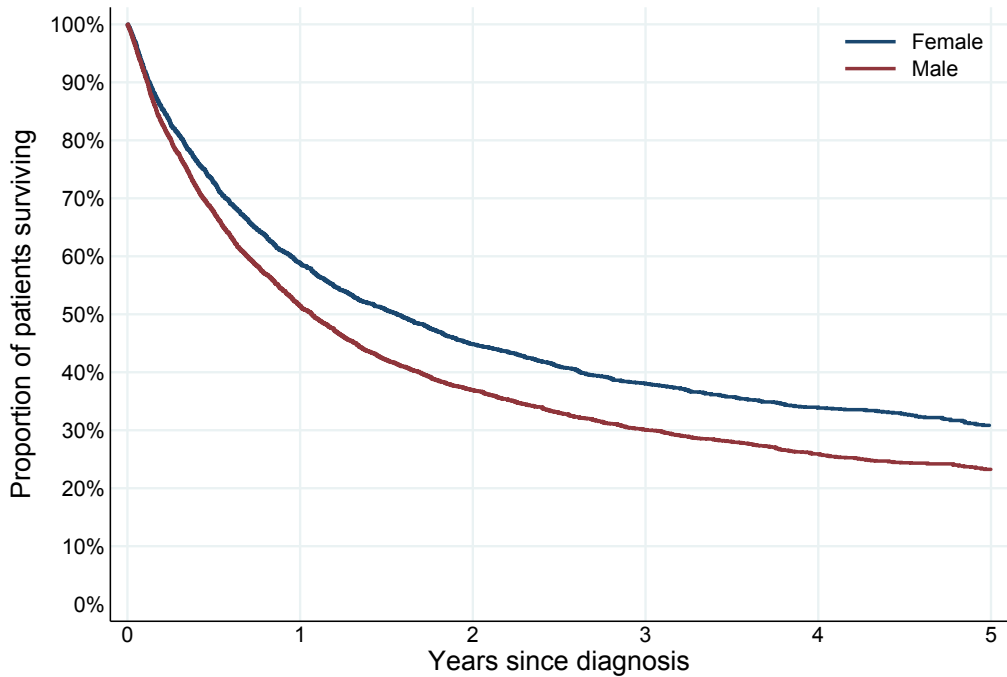
Based on 2011-2018 VLCR patient registrations, the median survival time is 1.23 years after diagnosis (Interquartile range: 1.17, 1.29 years). The Kaplan-Meier estimates show 54.6 % survival at one year after diagnosis and 26.5% at five years after diagnosis, Figure 4 and Table 1.

**TABLE 1: VLCR 2011-2018 CRUDE SURVIVAL RATES AT TIME INTERVALS AFTER DIAGNOSIS**

	Number diagnosed	Number deceased	Crude survival at time after diagnosis (95% Confidence Interval)		
			1 Year	2 Years	5 Years
<b>All patients</b>	8,308	5,677	54.6% (53.5 - 55.7)	40.3% (39.3 - 41.4)	26.5% (25.4 - 27.7)
<b>Sex</b>					
Female	3,579	2,285	58.8% (57.2 - 60.4)	44.8% (43.2 - 46.5)	30.8% (29.0 - 32.7)
Male	4,729	3,392	51.4% (50.0 - 52.9)	36.9% (35.5 - 38.3)	23.3% (21.8 - 24.7)
<b>Age Group</b>					
Less than 60 years	1,460	910	62.5% (59.9 - 64.9)	46.1% (43.5 - 48.6)	33.8% (31.1 - 36.6)
60 to 69 years	2,435	1,579	58.8% (56.8 - 60.7)	43.8% (41.9 - 45.8)	29.6% (27.5 - 31.8)
70 to 79 years	2,845	1,910	55.4% (53.6 - 57.2)	41.8% (39.9 - 43.6)	27.3% (25.2 - 29.3)
80 years and older	1,568	1,278	39.4% (37.0 - 41.8)	26.9% (24.7 - 29.1)	13.3% (11.2 - 15.7)
<b>Clinical stage</b>					
Stage I	905	245	90.9% (88.9 - 92.6)	82.2% (79.5 - 84.6)	65.1% (60.6 - 69.1)
Stage II	561	287	77.4% (73.7 - 80.6)	61.7% (57.5 - 65.6)	42.4% (37.2 - 47.4)
Stage III	1,613	1,005	67.9% (65.5 - 70.1)	49.8% (47.3 - 52.2)	32.3% (29.5 - 35.0)
Stage IV	3,341	2,890	34.0% (32.4 - 35.6)	18.9% (17.6 - 20.3)	9.6% (8.3 - 10.9)
Not stated	1,888	1,250	55.6% (53.3 - 57.8)	43.7% (41.5, 46.0)	28.9% (26.4, 31.4)

Notes: Crude survival rates are presented with no adjustment for risk factors.

FIGURE 5: VLCCR SURVIVAL ANALYSIS BY SEX 2011 – 2018

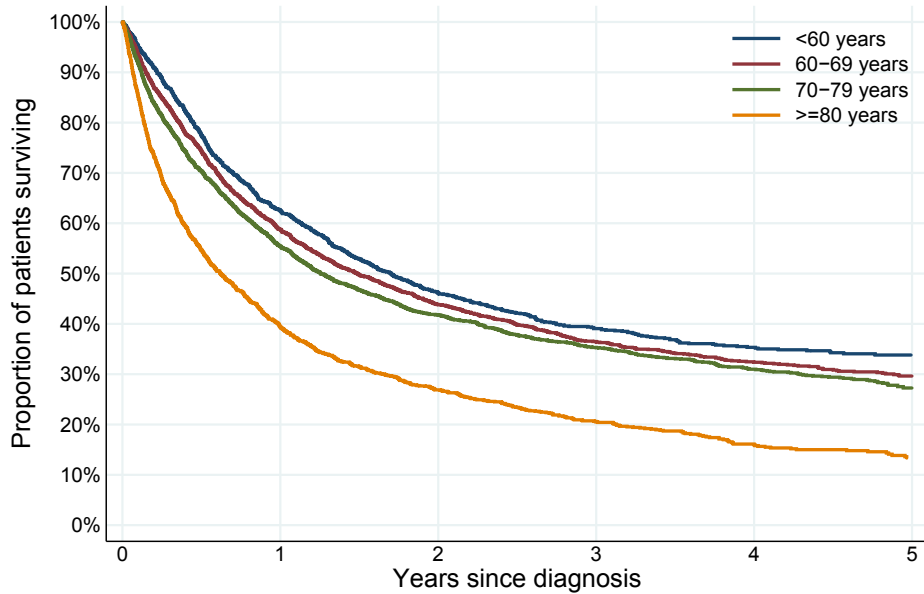


Number at risk by sex

Female	3,579	2,105	1,407	839	485	276
Male	4,729	2,433	1,519	878	521	299

Female survival was higher at one year after diagnosis than male survival (Female: 58.8%; Male: 51.4%) and also at five years after diagnosis (Female: 30.8%, Male: 23.3%), Table 1 and Figure 5.

FIGURE 6: VLCCR SURVIVAL ANALYSIS BY AGE GROUP 2011 – 2018

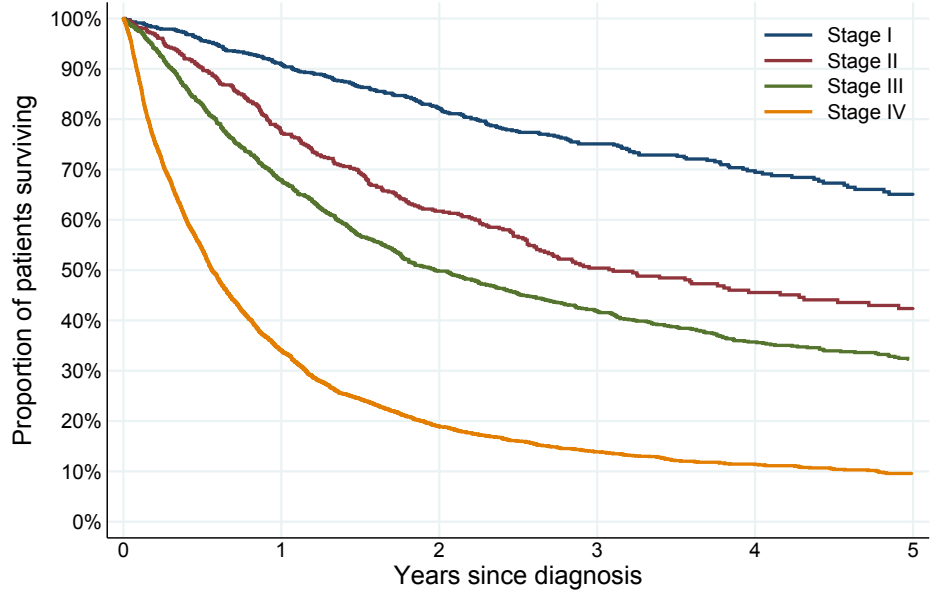


Number at risk by age

<60 years	1,460	912	599	369	226	128
60-69 years	2,435	1,431	921	524	328	201
70-79 years	2,845	1,577	1,031	627	347	194
>=80 years	1,568	618	375	197	105	52

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 39.4%, whereas survival at one year for those diagnosed before 60 years of age is 62.5%, Table 1 and Figure 6.

FIGURE 7: VLCR SURVIVAL ANALYSIS BY CLINICAL STAGE 2011 – 2018



Number at risk by clinical stage

Stage I	905	823	615	367	221	123
Stage II	561	434	289	164	98	65
Stage III	1,613	1,095	742	468	271	158
Stage IV	3,341	1,137	543	265	144	75

Crude survival rates are lower for patients presenting at a later clinical stage; survival at one year for Stage I patients is 90.9% and only 34.0% for Stage IV patients, Table 1 and Figure 7.

# Lung Foundation Australia



“Lung cancer remains Australia’s leading cause of cancer death and has the poorest five year survivorship of just 17%. Behind these statistics are everyday Australians and now more than ever high quality data is needed to inform health policy at state and federal level and transform support for patients. Equitable services, free from stigma, will only be enhanced if we have evidence. Lung Foundation supports the development of a national lung cancer registry to ensure this evidence has the power to transform lives.”

MARK BROOKE  
CEO, LUNG FOUNDATION AUSTRALIA

# VLCR PATIENT CHARACTERISTICS IN 2018

AGE, SEX, SMOKING STATUS, INDIGENOUS STATUS, COUNTRY OF BIRTH, PREFERRED LANGUAGE AND SOCIO-ECONOMIC PROFILE.

FIGURE 8: VLCR 2018 SEX

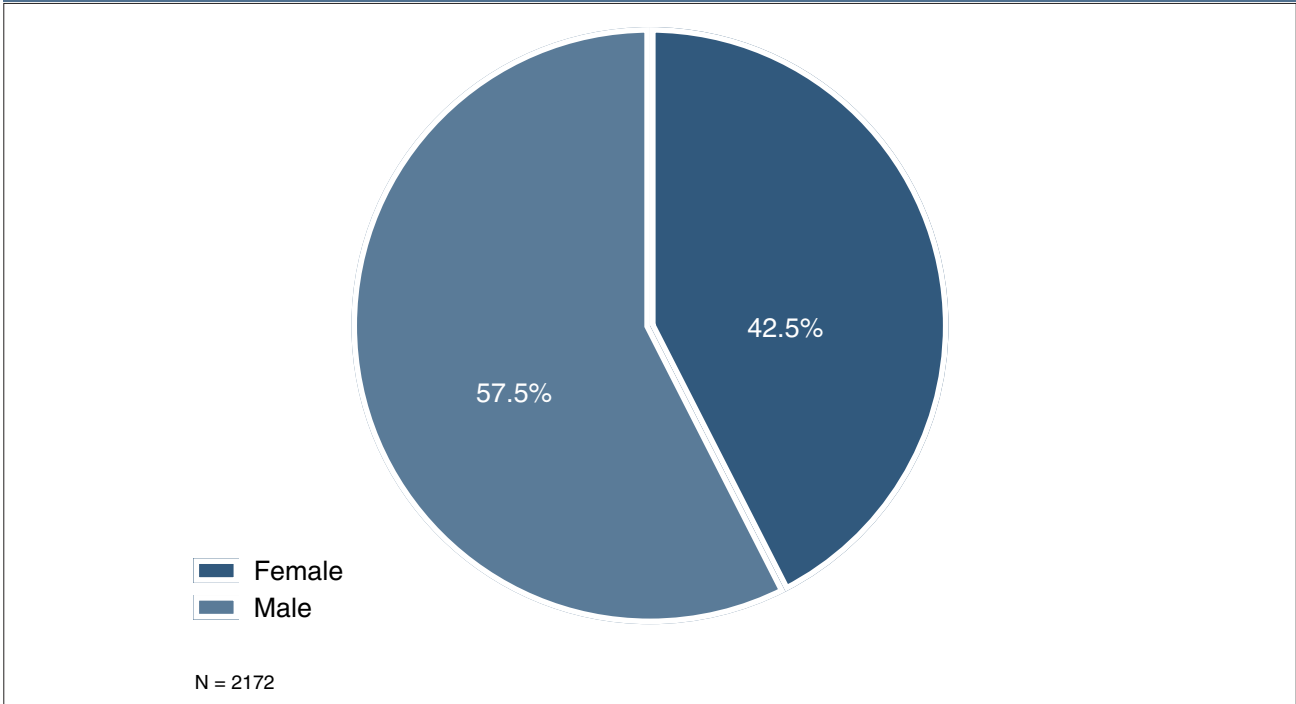
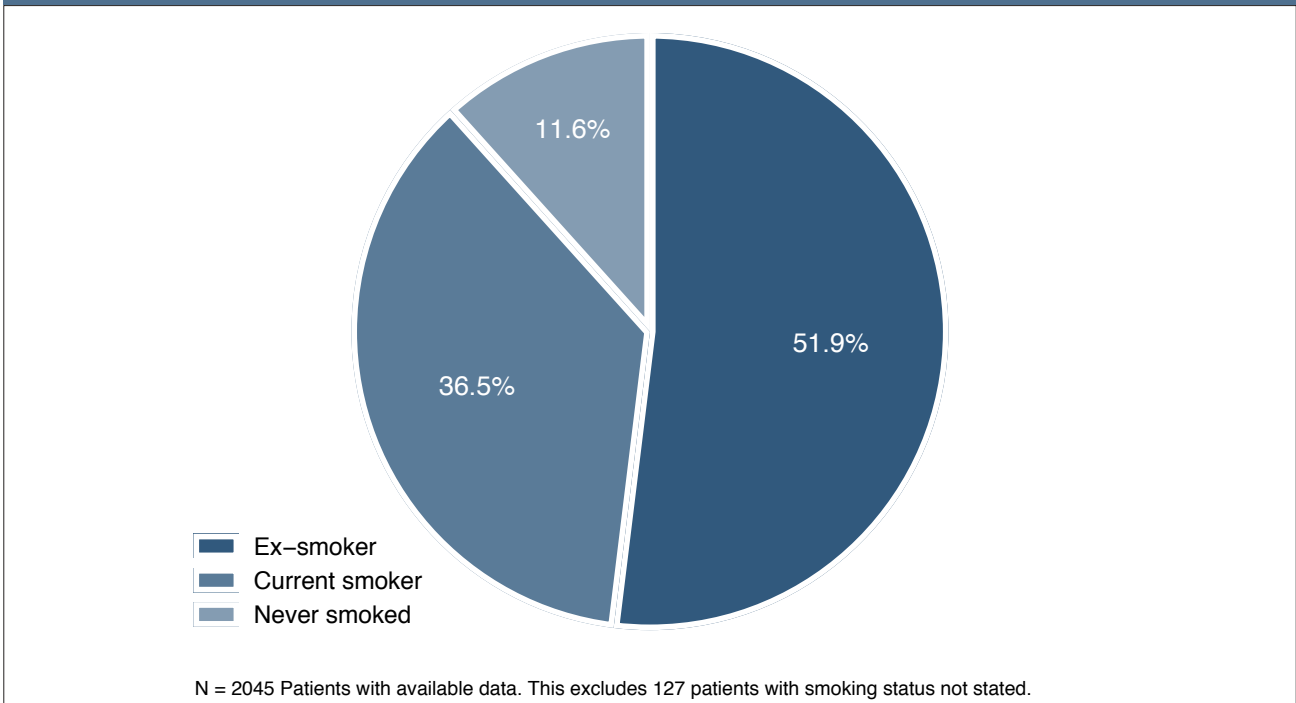


FIGURE 9: VLCR 2018 SMOKING STATUS



In the 2018 period there were a greater number of male than female participants, Figure 8 (57.5 vs 42.5%). Approximately half (51.9%) of participants with available smoking status identified as an ex-smoker, 36.5% were current smokers and 11.6% had never smoked, Figure 9.

**TABLE 2: VLCR 2018 LANGUAGE, BIRTHPLACE AND INDIGENOUS STATUS**

	Number	Percent
<b>Region of Birth</b>		
Australia	1,292	59%
England	122	6%
Italy	89	4%
Greece	79	4%
Scotland	25	1%
Poland	14	1%
Germany	27	1%
Malta	26	1%
Netherlands	30	1%
China	43	2%
Other	425	20%
<b>Total</b>	<b>2,172</b>	<b>100%</b>

<b>Preferred Language</b>		
English	1,916	88%
Greek	44	2%
Italian	34	2%
Mandarin	29	1%
Vietnamese	29	1%
Cantonese	18	1%
Russian	7	0%
Turkish	14	1%
Croatian	8	0%
Macedonian	12	1%
Other	61	3%
<b>Total</b>	<b>2,172</b>	<b>100%</b>

<b>Indigenous Status</b>		
Indigenous	19	0.9%
Non-Indigenous	2,146	98.8%
Unknown	7	0.3%
<b>Total</b>	<b>2,172</b>	<b>100%</b>

In the 2018 period the majority of VLCR participants were born in Australia, Table 2 (59%).

English was identified as the first language by 88% of participants and 0.9% of participants identified themselves as Indigenous Australians, Table 2.

ATSI identification is provided by participating site administrative data. Therefore, if ATSI patients are not admitted to a participating institution, or do not identify their ABTSI status on admission, they will not be represented in these figures, Table 2.

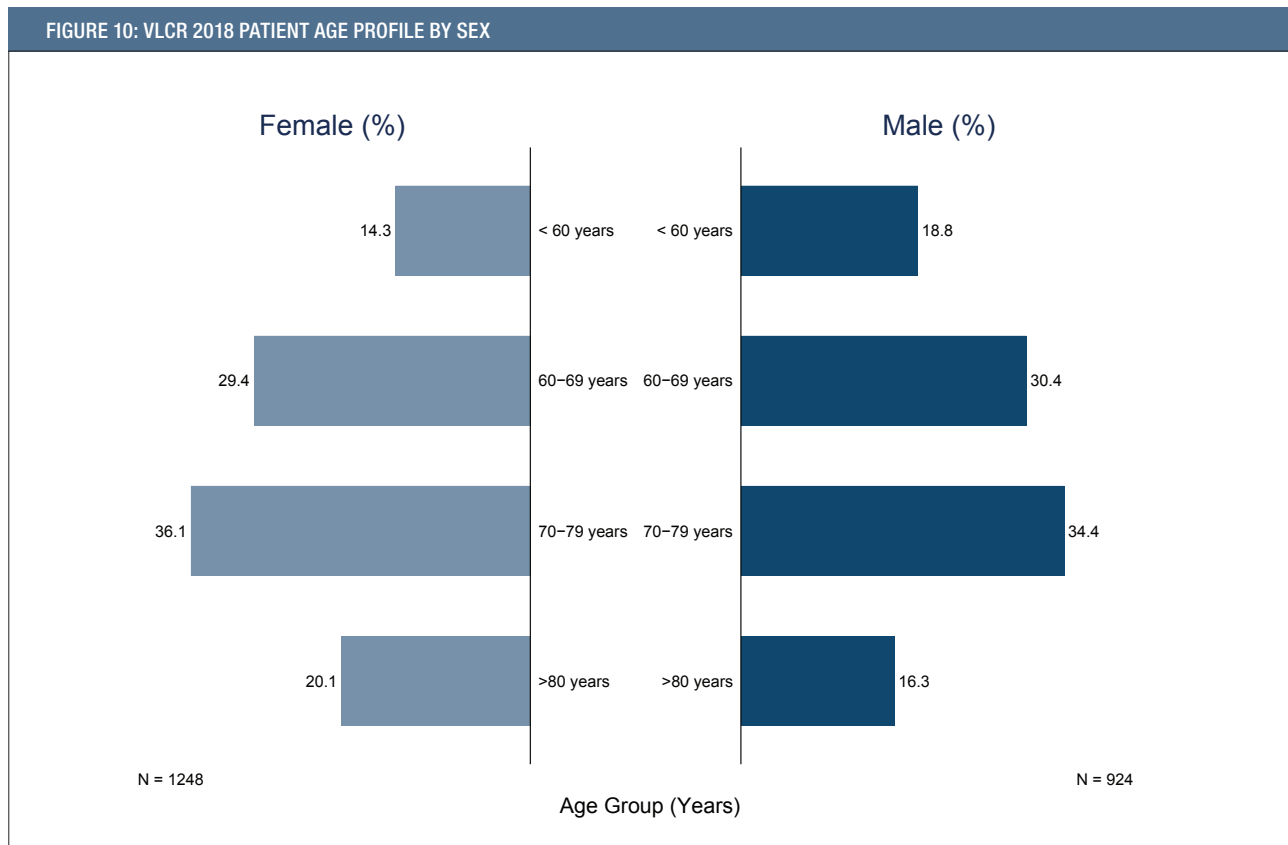


TABLE 3: VLCR 2018 PATIENT AGE GROUPING BY SEX

	Female	Male	p-value (test)
<b>Age</b>	N = 924 (42.5%)	N = 1,248 (57.5%)	
Mean (Standard Deviation)	69.0 (10.8)	70.4 (10.7)	0.003 (Two sample t-test)

Male participants were on average, 1.4 years older than females at diagnosis, Table 3 (69.0 vs 70.4; p=0.03).

FIGURE 10: VLCR 2018 PATIENT AGE PROFILE BY SEX



The highest age at diagnosis incidence is in the 70-79 year age groups for both males and females, Figure 10 (34.4% and 36.1%). Those diagnosed prior to 60 years of age represent 18.8% (male registrations) and 14.3% (female registrations), Figure 10.

The VLCR does not collect individual level data on income, education levels or occupation of participants. However, an indication of the level of socio-economic advantage or disadvantage of VLCR participants within the registry was gained from the Australian Bureau of Statistics 2016 Socio-Economic Index for Australia (SEIFA) using the postcode area in which VLCR patients lived at the time of diagnosis [13].

TABLE 4: 2018 PATIENT SOCIO-ECONOMIC PROFILE		
SEIFA – IRSAD Decile	Number	Percent
1-10% (most disadvantaged)	243	11.19%
11-20%	206	9.48%
21-30%	162	7.46%
31-40%	206	9.48%
41-50%	132	6.08%
51-60%	303	13.95%
61-70%	224	10.31%
71-80%	226	10.41%
81-90%	270	12.43%
91-100% (most advantaged)	199	9.16%
Unknown	1	0.05%
<b>Total</b>	<b>2,172</b>	<b>100%</b>

Table 4 shows the Index of Relative Socio-economic Advantage and Disadvantage (IRSAD) distribution of VLCR patients according to the socio-economic profile of the areas in which they lived when diagnosed in 2018.

Of the 2018 VLCR patient cohort, the patient socio-economic profile appears dispersed, 21.59% lived in postal areas at diagnosis that were ranked in the top 20% (most advantaged areas). On the other socio-economic spectrum, 20.67% of the 2018 VLCR patients lived in areas ranked in the lowest 20% (most disadvantaged areas).



“Living with lung cancer in the current day is no longer the death sentence it once was. There is so much more to look forward to and be hopeful for, now more than ever before, particularly as the treatment options for patients continue to expand and become more durable, the stigma gradually fades away and our community of voices are beginning to grow. But the job is far from being over! There is still so much work to be done and still so many gaps to be filled before we can achieve the ultimate success of dramatically improving outcomes and eventually finding a cure for this disease. Without a National Lung Cancer Registry to help inform clinical research and without a significant boost in funding for research, we will continue to be challenged by the high burden of disease and inequality divide between cancers and their outcomes. My hope is that all levels of our health sector will work together, to help patients like me to continue to live my life as a wife and mother of two small children.”

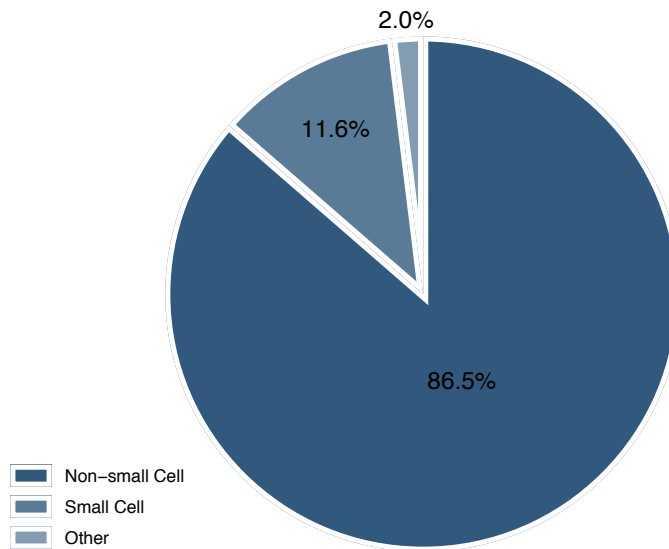
LISA BRIGGS  
LUNG CANCER PATIENT ADVOCATE  
VLCR CONSUMER REPRESENTATIVE

# VLCCR LUNG CANCER TYPES IN 2018

Cancer cell type is presented in Figure 11 below for the 2018 patient cohort with available data. Overall Non-Small Cell Lung Cancer (NSCLC) was the most frequent histology identified at 86.5%, Small Cell Lung Cancer (SCLC) comprised 11.6%, and 2.0% presented with other lung cancer types. Lung cancer type was not identifiable for 123 patients diagnosed in 2018. This includes 112 patients who had a clinical diagnosis (no histological test recorded) and 11 patients who had unknown morphology.

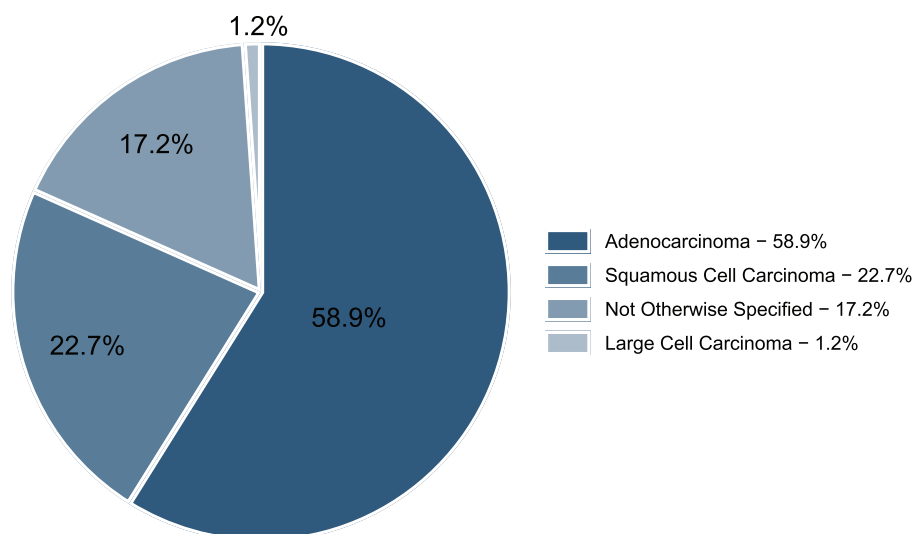
Of the 1,772 diagnosed with NSCLC in 2018, 58.9% had Adenocarcinoma, 22.7% had Squamous Cell Carcinoma, 1.2% had Large Cell Carcinoma and 17.2% were Not Otherwise Specified (NOS), Figure 12.

FIGURE 11: VLCCR 2018 LUNG CANCER TYPE



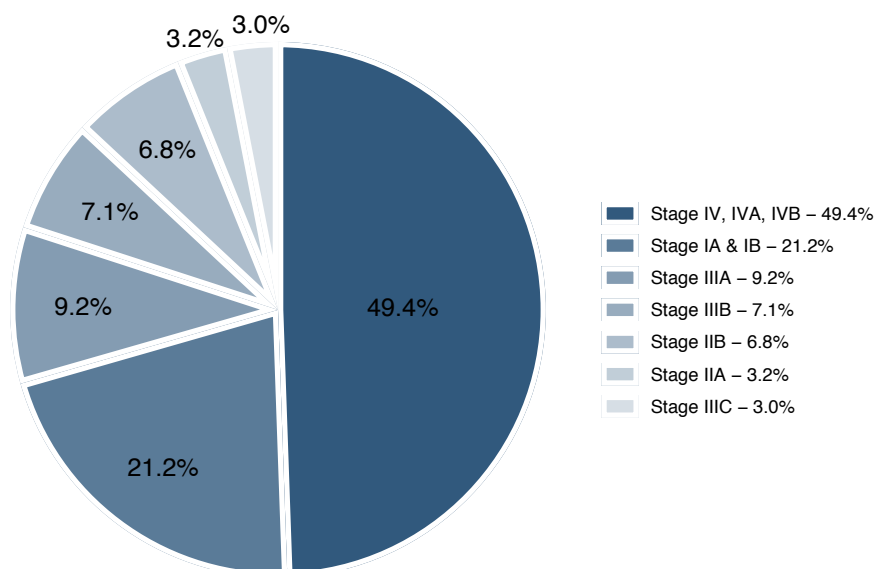
N = 2049 Patients with available data. This excludes 123 patients with lung cancer type not stated.

FIGURE 12: VLCCR 2018 NSCLC TYPE



N = 1772 Patients with Non-small Cell Lung Cancer

FIGURE 13: VLCR 2018 CLINICAL STAGING FOR NSCLC TYPE



N = 1493 Patients with Non-small Cell Lung Cancer and available clinical stage

Documentation of clinical stage was not recorded for 279 (15.7%) of the 1,772 NSCLC participants. Of the 1493 patients with NSCLC and documented clinical stage, the majority had advanced metastatic disease at presentation (Stage IV - 49.4%), while 31.2% had localised, early stage disease (Stage I-II), Figure 13.

## VLCR PATIENT PERFORMANCE STATUS IN 2018

TABLE 5: VLCR 2018 PATIENT ECOG STATUS AT DIAGNOSIS

ECOG status at diagnosis	Number	Percent
0—Fully active, able to carry on all normal activity without restriction	549	25.3%
1—Restricted in physically strenuous activity but ambulatory and able to carry out light work	618	28.5%
2—Ambulatory and capable of all self-care but unable to carry out any work activities.	196	9.0%
3—Capable of only limited self-care, confined to bed or chair more than 50% of waking hours	103	4.7%
4—Completely disabled, not able to self-care, totally confined to bed or chair	13	0.6%
Unknown	693	31.9%
<b>Total</b>	<b>2,172</b>	<b>100%</b>

Documentation of performance status was unavailable for n=693 (31.9%) of participants. For those with documented performance status n=1167 (53.8%) had good performance status (ECOG 0-1) and n=312 (14.3%) had poor performance status (ECOG ≥ 2), Table 5.

# VLCR PATIENT CHARACTERISTICS AND TREATMENT IN 2018 BY CLINICAL STAGE

TABLE 6: VLCR 2018 PATIENT CHARACTERISTICS BY CLINICAL STAGE

Clinical Stage	I	II	III	IV	Cannot be assessed	Total
<b>Victoria</b>	338	164	316	957	397	2,172

<b>Sex</b>						
Female	180 (53%)	70 (43%)	120 (38%)	385 (40%)	169 (43%)	924 (43%)
Male	158 (47%)	94 (57%)	196 (62%)	572 (60%)	228 (57%)	1,248 (57%)

<b>Age</b>						
< 50 years	10 (3%)	4 (2%)	19 (6%)	44 (5%)	6 (2%)	83 (4%)
50-59 years	45 (17%)	16 (10%)	39 (12%)	122 (13%)	48 (12%)	270 (12%)
60-69 years	100 (30%)	56 (34%)	97 (31%)	296 (31%)	99 (25%)	648 (30%)
70-79 years	135 (40%)	64 (39%)	105 (33%)	321 (34%)	144 (36%)	769 (35%)
≥80 years	48 (14%)	24 (15%)	56 (18%)	174 (18%)	100 (25%)	402 (19%)

<b>IRSAD Summary</b>						
81-100%	64 (19%)	29 (18%)	63 (20%)	203 (21%)	110 (28%)	469 (22%)
61-80%	68 (20%)	33 (20%)	67 (21%)	207 (22%)	75 (19%)	450 (21%)
41-60%	57 (17%)	36 (22%)	61 (19%)	207 (22%)	74 (19%)	435 (20%)
21-40%	69 (20%)	27 (16%)	54 (17%)	149 (16%)	69 (17%)	368 (17%)
1-20%	80 (24%)	38 (23%)	71 (22%)	191 (20%)	69 (17%)	449 (21%)
Unknown	0 (0%)	1 (.06%)	0 (0%)	0 (0%)	0 (0%)	1 (.05%)

<b>Site Type</b>						
Metropolitan Public	249 (74%)	117 (71%)	211 (67%)	674 (70%)	253 (64%)	1,504 (69%)
Metropolitan Private	48 (14%)	15 (9%)	31 (10%)	92 (10%)	65 (16%)	251 (12%)
Regional	41 (12%)	32 (20%)	74 (23%)	191 (20%)	79 (20%)	417 (19%)

<b>ATSI</b>						
ATSI	1 (0.3%)	1 (0.6%)	6 (2%)	9 (0.9%)	3 (0.8)	20 (0.9%)
Non ATSI	337 (99.7%)	162 (98.8%)	308 (97%)	945 (98.7%)	394 (99.2%)	2,146 (98.8%)
Unknown	0 (0%)	1 (0.6%)	2 (1%)	3 (0.3%)	0 (0%)	6 (0.3%)

<b>Reviewed at MDM</b>						
Yes	278 (82%)	147 (90%)	263 (83%)	559 (58%)	243 (61%)	1,490 (69%)
No	60 (18%)	17 (10%)	53 (17%)	398 (42%)	154 (39%)	682 (31%)

TABLE 7: VLCR 2018 PATIENT TREATMENT BY CLINICAL STAGE

Clinical Stage	I	II	III	IV	Cannot be assessed	Total
<b>Victoria</b>	338	164	316	957	397	2,172
<b>Any Treatment*</b>						
Had anti-cancer treatment	326 (96%)	153 (93%)	286 (91%)	728 (76%)	296 (75%)	1,789 (82%)
No anti-cancer treatment	12 (4%)	11 (7%)	30 (9%)	229 (24%)	101 (25%)	383 (18%)

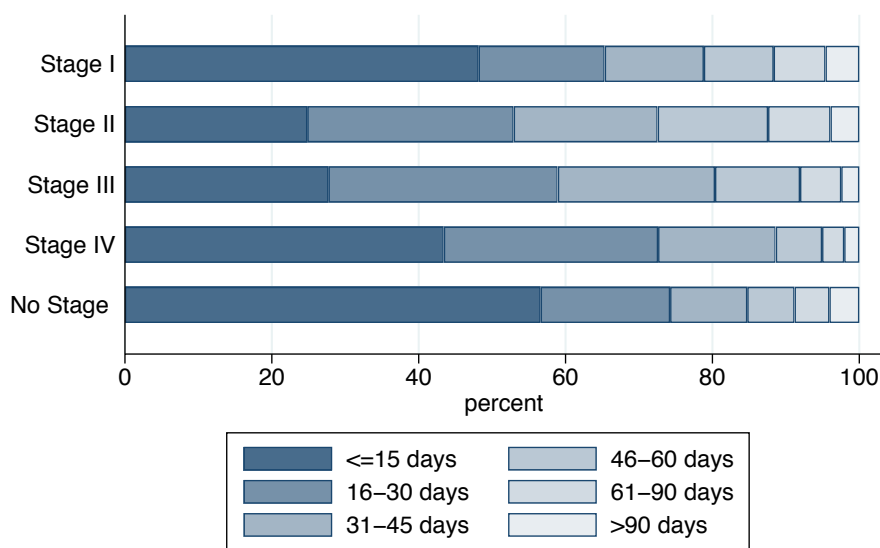
<b>Systemic Anti-Cancer treatment**</b>						
Yes	43 (13%)	84 (51%)	217 (69%)	580 (61%)	130 (33%)	1,054 (49%)
No	289 (86%)	77 (47%)	88 (28%)	323 (34%)	252 (63%)	1,029 (47%)
Declined	6 (2%)	3 (2%)	11 (3%)	54 (6%)	15 (4%)	89 (4%)

<b>Radiotherapy treatment</b>						
Yes	99 (29%)	69 (42%)	223 (71%)	418 (44%)	113 (28%)	922 (42%)
No	236 (70%)	91 (55%)	82 (26%)	502 (52%)	271 (68%)	1,182 (54%)
Declined	6 (2%)	4 (2%)	11 (3%)	37 (4%)	13 (3%)	71 (3%)

<b>Surgical Resection</b>						
NSCLC clinical stage	317	149	289	738	279	1,772
Yes	225 (71%)	79 (53%)	33 (11%)	4 (0.5%)	135 (48%)	476 (27%)
No	87 (27%)	67 (45%)	254 (88%)	773 (99.4%)	139 (50%)	1,280 (72%)
Declined	5 (2%)	3 (2%)	2 (1%)	1 (0.1%)	5 (2%)	16 (1%)

\*Captures first treatment for chemotherapy, radiotherapy or surgical resection  
 \*\*Systemic anti-cancer treatment includes chemotherapy and targeted treatment immunotherapy

FIGURE 14: VLCR 2018 TIME TO TREATMENT BY STAGE



# CLINICAL QUALITY INDICATORS

The VLCR collects and reports on data relating to 21 clinical quality indicators. The VLCR clinical quality indicators have been developed by an expert working group (see Appendix E).

Hospital performance on each VLCR indicator are risk-adjusted and benchmarked against the cohort, and then reported to participating sites for the purposes of quality improvement. 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 [12].

## HOW TO INTERPRET FUNNEL PLOTS

Clinical registries 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, the horizontal axis (x-axis) measures the number of cases being examined e.g. the number of subjects for the particular indicator. The vertical axis (y-axis) measures the percentage of cases meeting a clinical indicator being reported ( see Figure 15).

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

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

Each institution dot is coloured depending on where it falls compared to the 95% and 99.8% control limits. Blue dots represent institution groups that fall within the control limits and therefore are not deemed statistical outliers. Orange dots represent institution groups that fall outside the 95% control limits and red dots represent institution groups that fall outside the 99.8% control limits. The red dots are deemed statistical outliers (more than 3 standard deviations from the mean in either direction). However, it is important to note that these do not necessarily indicate shortcomings in care, or outstanding care. Further investigation is always required to determine whether an institution is a true outlier and the clinical importance of the result.

**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 standard deviations of the benchmark.

**Special cause variation (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 standard deviations of the benchmark.

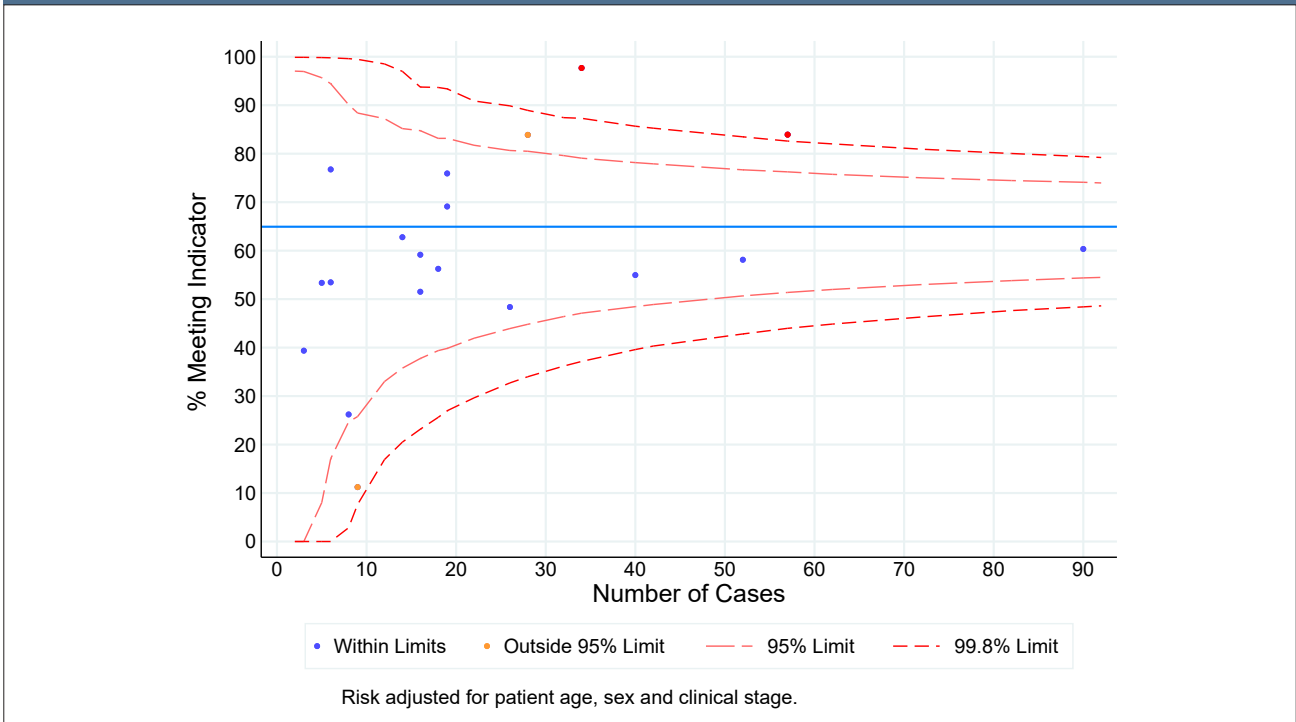
We undertook risk-adjusted funnel plot analysis because the VLCR is an observational study design and we wanted to account for potential confounders. Patient sex, age and clinical stage were determined to be clinically important and were included in all risk-adjusted funnel plots except where otherwise specified for reasons such as collinearity, 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%



FIGURE 15: FUNNEL PLOT EXAMPLE



Note: Risk adjusted for patient sex, age and clinical stage.

## SELECTED QUALITY INDICATORS

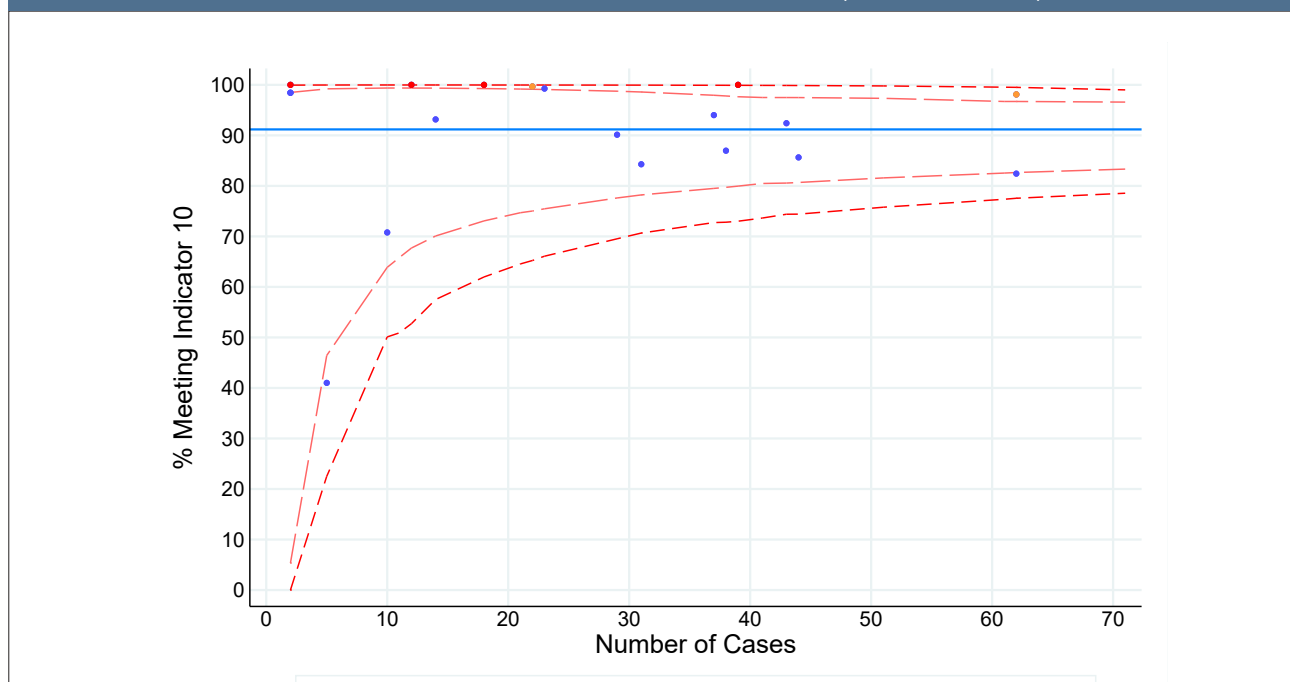
The following quality indicators are grouped to reflect six specific aims to improve core quality of health by delivering health care that is: **safe, effective, patient-centered, timely, efficient and equitable** [14].

Appendix E lists data used to calculate each quality indicator. Funnel plots risk adjust for sex, age or clinical stage (where deemed appropriate for each indicator) and are provided for each indicator representing the domains of care described above (Figures 16-25). Participating sites are de-identified and represented by numbers 1–19.

# SAFE HEALTH CARE

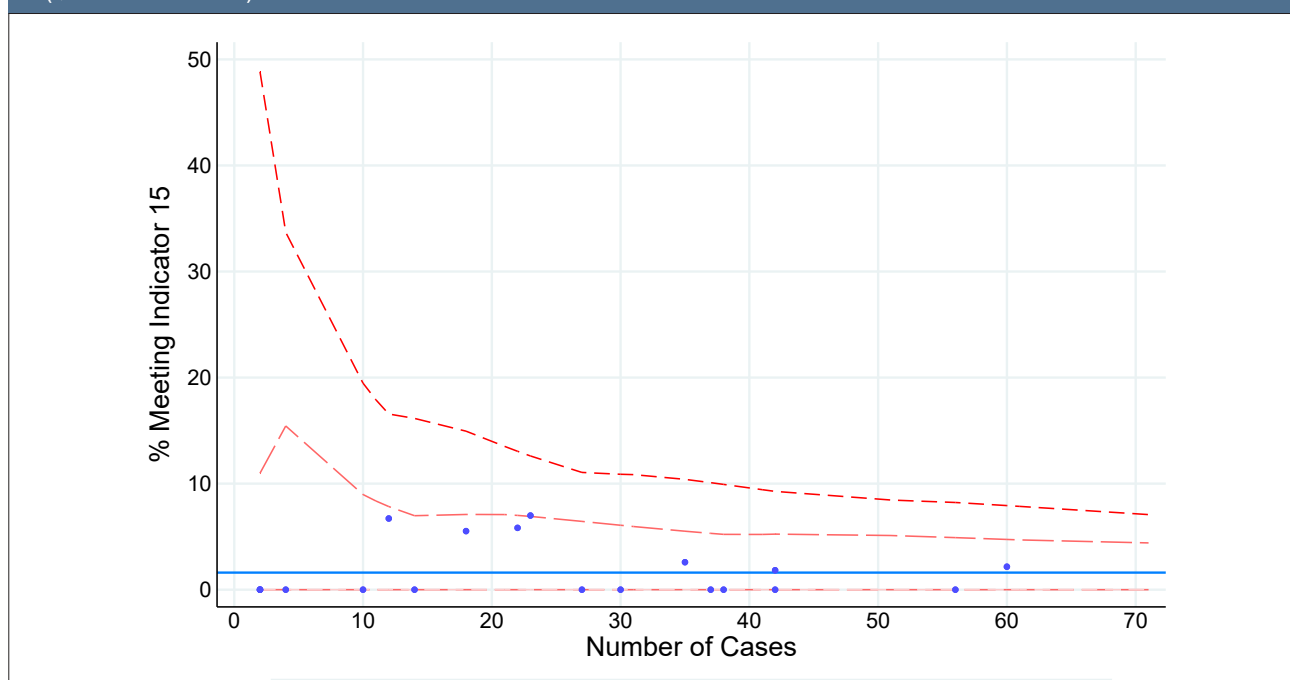
Safety in Healthcare may be defined as the, **‘Degree to which health care processes avoid, prevent, and ameliorate adverse outcomes or injuries that stem from the process of health care itself’** [14]. Two indicators have been chosen to reflect patient safety. First, the utilisation of PET scanning prior to resection, as another measure of the appropriate preoperative evaluation in the prevention of inappropriate or futile surgery. Second, mortality rate occurring within the first 30 days following resection, as a measure of surgical selection, operative and perioperative management.

FIGURE 16: PROPORTION OF PATIENTS UNDERGOING RESECTION WITH DOCUMENTED PET SCAN (QUALITY INDICATOR 10)



N = 495: Total cohort mean 91%.  
Notes: Risk adjusted for patient sex, age. The use of this funnel plot to identify potential outliers must be made with caution due to small numbers.

FIGURE 17: PROPORTION OF PATIENTS WITH NSCLC WHO HAVE HAD A RESECTION AND DATE OF DEATH WITHIN 30 DAYS OF SURGERY (QUALITY INDICATOR 15)

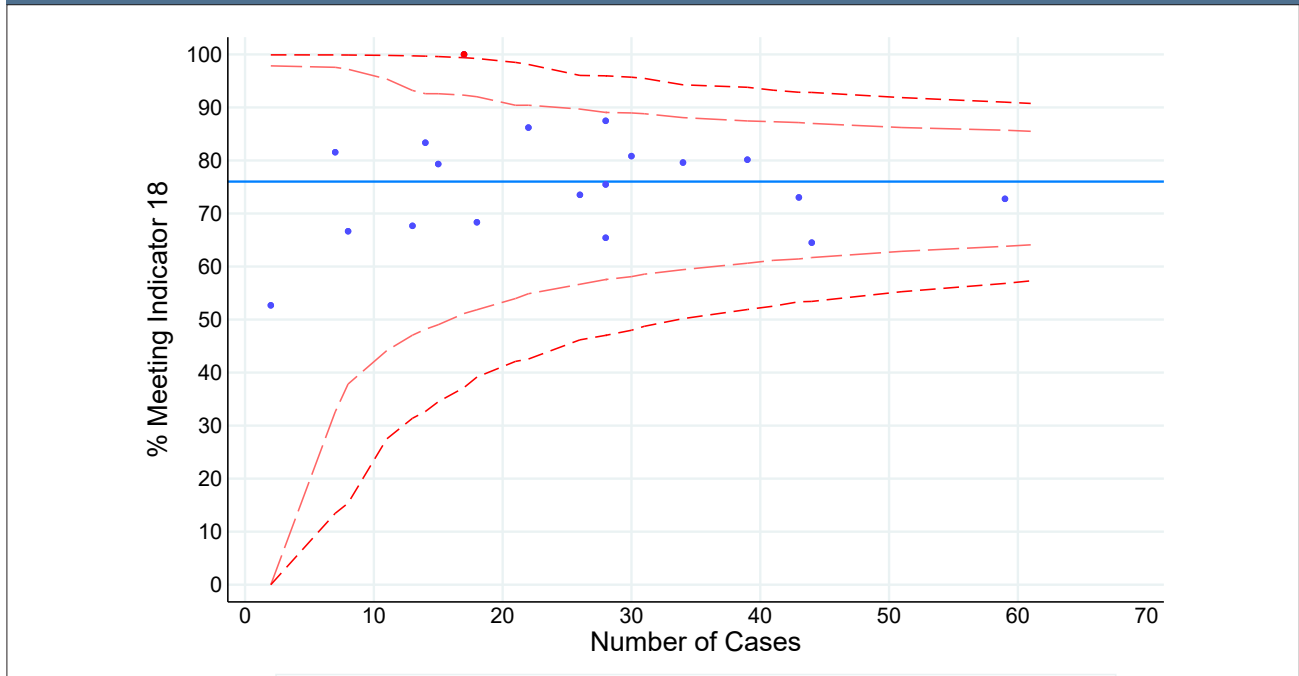


N = 476: Total cohort mean 2%.  
Notes: Risk adjusted for patient sex, age and clinical stage. The use of this funnel plot to identify potential outliers must be made with caution due to small numbers.

# EFFECTIVE HEALTH CARE

Effective healthcare may be defined as, ‘The extent to which improvements in health care are attained, using available evidence-based healthcare measures’ [14]. Two indicators have been chosen to reflect healthcare effectiveness. First, the proportion of clinically appropriate patients in whom chemotherapy is commenced, and second, whether early stage NSCLC patients are resected.

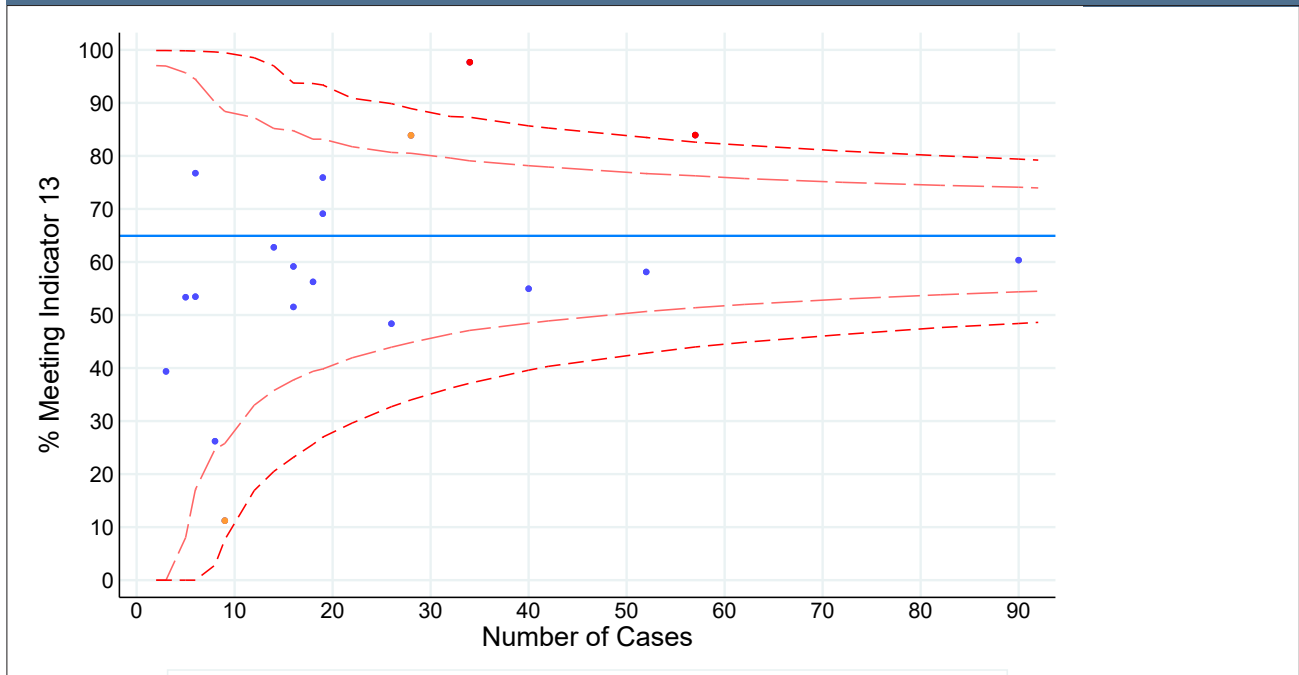
FIGURE 18: PROPORTION OF PATIENTS WITH NSCLC (CLINICAL STAGE III B AND IV) WHO HAVE ECOG (0–1) WHO HAVE COMMENCED CHEMOTHERAPY (QUALITY INDICATOR 18)



N = 475. Total cohort mean 76%.

Notes: Risk adjusted for patient sex, age, and clinical stage. The use of this funnel plot to identify potential outliers must be made with caution due to small numbers.

FIGURE 19: PROPORTION OF PATIENTS WITH NSCLC (CLINICAL STAGE I OR II) WHO HAVE HAD A SURGICAL RESECTION (QUALITY INDICATOR 13)



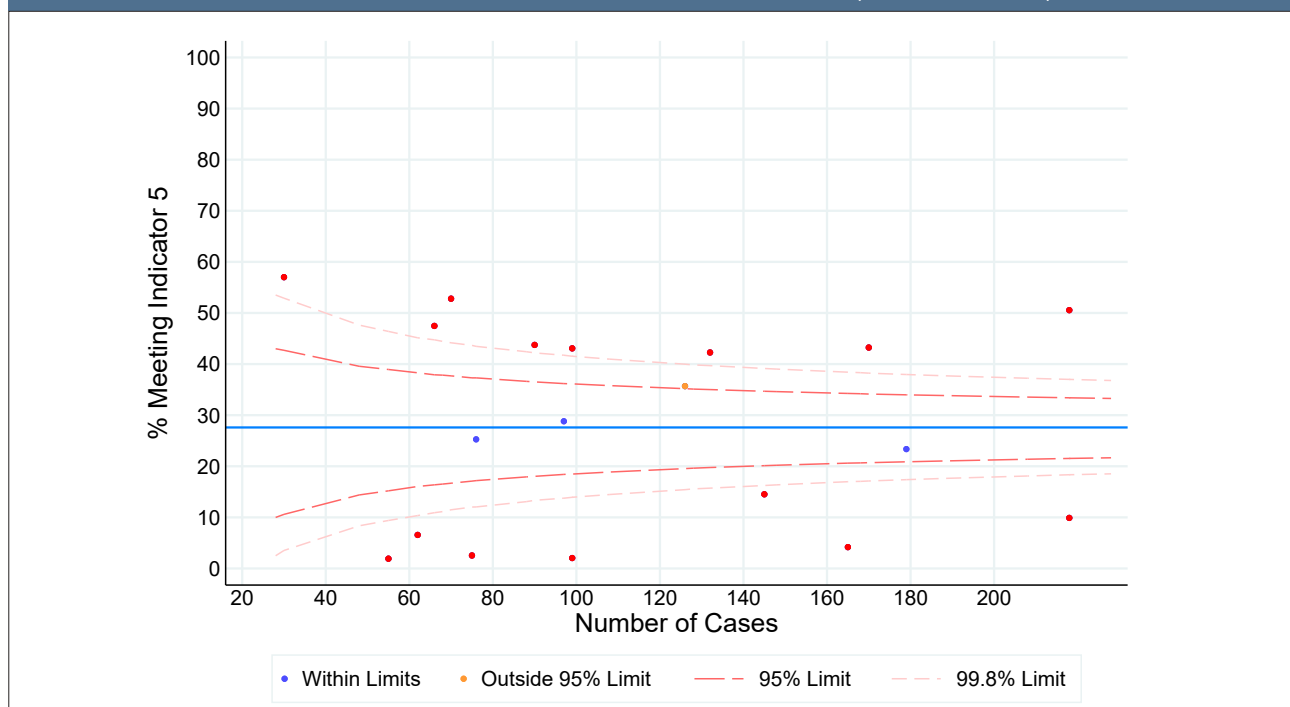
N = 466. Total cohort mean 65%.

Notes: Risk adjusted for patient sex, age and clinical stage. The use of this funnel plot to identify potential outliers must be made with caution due to small numbers and poor data completeness.

# PATIENT-CENTRED HEALTH CARE

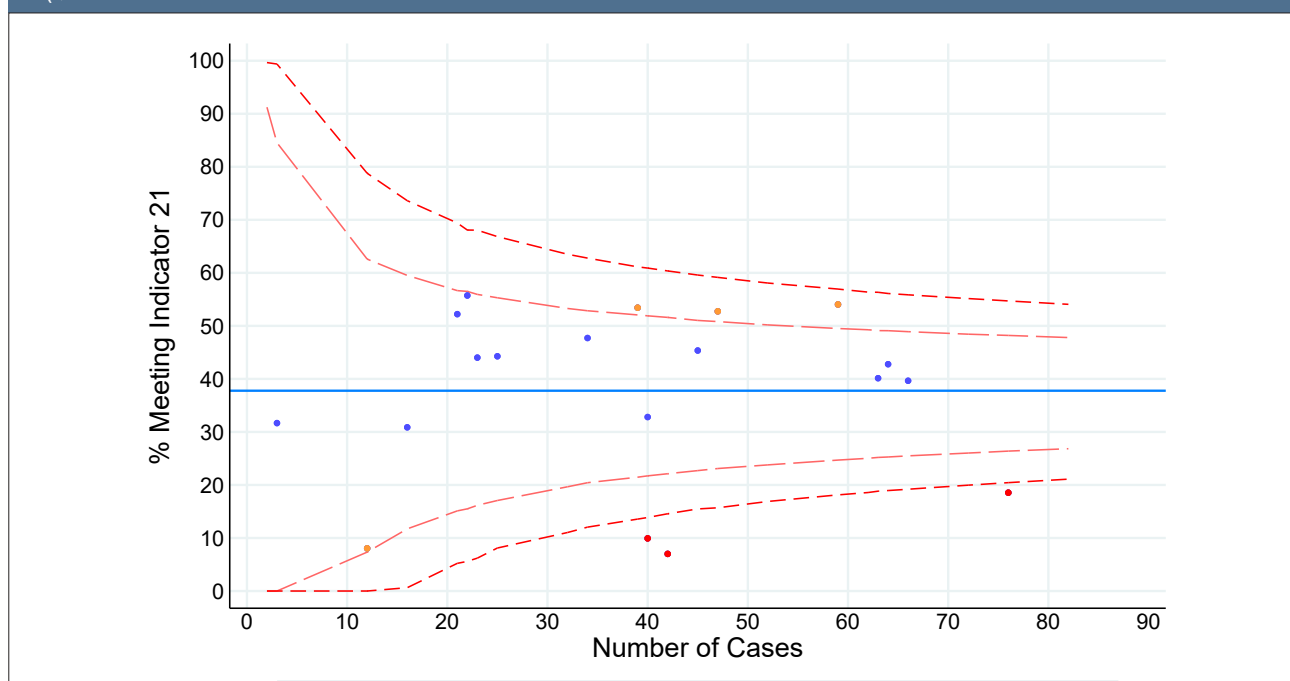
Patient-centred healthcare may be defined as, ‘Providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions’ [14]. Two indicators have been chosen to reflect patient-centred healthcare. First, the proportion of patients with documented screening for supportive care and second, the proportion of patients with NSCLC (stage IV) referred to any palliative care services within 8 weeks of diagnosis.

FIGURE 20: PROPORTION OF PATIENTS WITH DOCUMENTED SCREENING FOR SUPPORTIVE CARE (QUALITY INDICATOR 5)



N = 2,172. Total cohort mean 28%.  
Notes: Risk adjusted for patient sex, age.

FIGURE 21: PROPORTION OF PATIENTS WITH NSCLC (STAGE IV) REFERRED TO ANY PALLIATIVE CARE SERVICES WITHIN 8 WEEKS OF DIAGNOSIS (QUALITY INDICATOR 21)

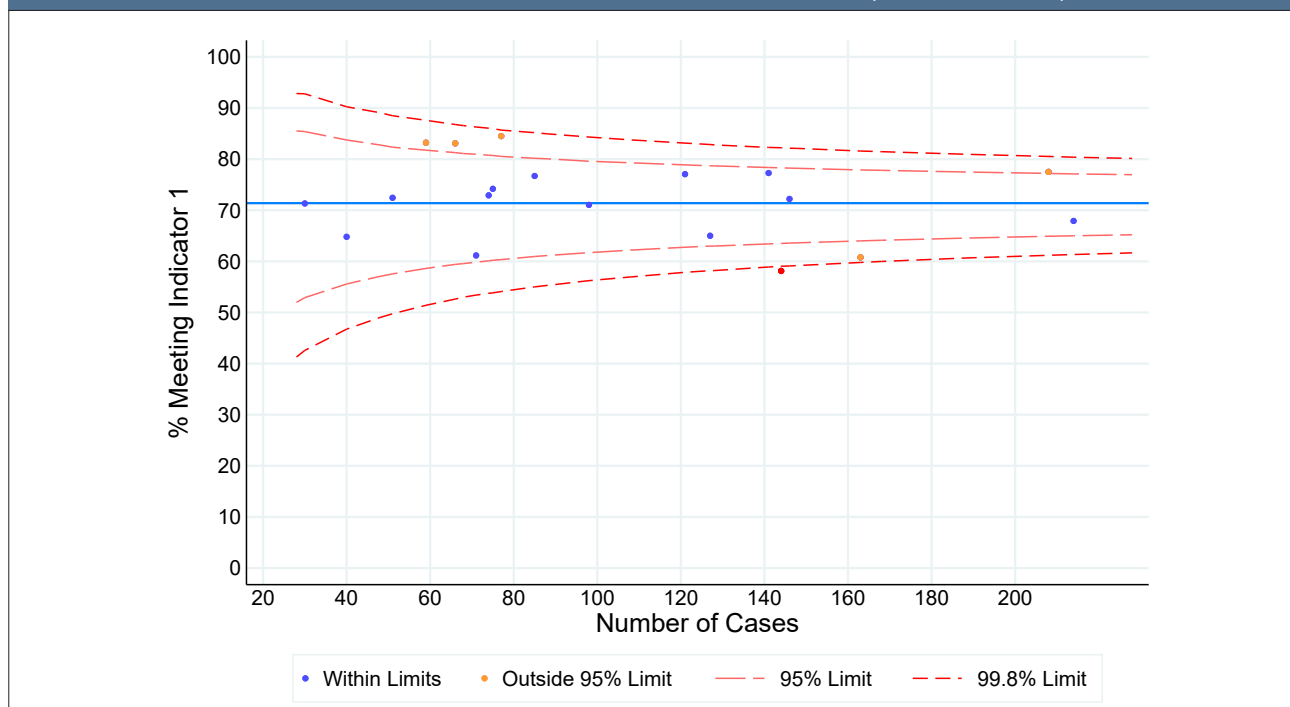


N = 737. Total cohort mean 38%.  
Notes: Risk adjusted for patient sex, age. The use of this funnel plot to identify potential outliers must be made with caution due to small numbers.

# TIMELY HEALTH CARE

Timely healthcare may be defined as, ‘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’ [14]. Two indicators have been chosen to reflect timeliness of healthcare. First the proportion of patients in whom a diagnosis is achieved within 28 days of referral, and second, the proportion of subjects who undergo surgical resection within 14 days of diagnosis.

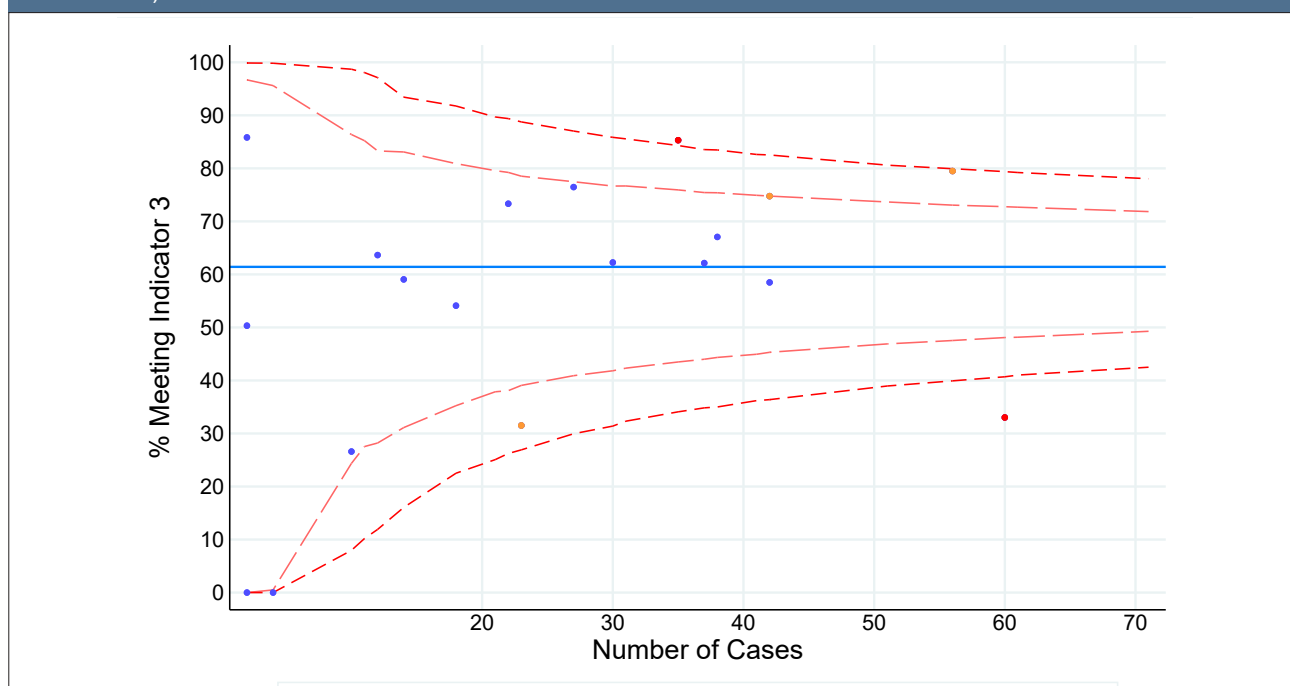
FIGURE 22 PROPORTION OF PATIENTS WHERE REFERRAL TO DIAGNOSIS DATE IS WITHIN 28 DAYS (QUALITY INDICATOR 1)



N = 1,990. Total cohort mean 72%.

Notes: Risk adjusted for patient sex, age and clinical stage. Referral is correspondence from a primary care provider (usually GP) or specialist requesting further investigation of suspected lung cancer

FIGURE 23: PROPORTION OF PATIENTS WITH NSCLC WHERE TIME FROM DIAGNOSIS TO SURGICAL RESECTION IS WITHIN 14 DAYS (QUALITY INDICATOR 3)



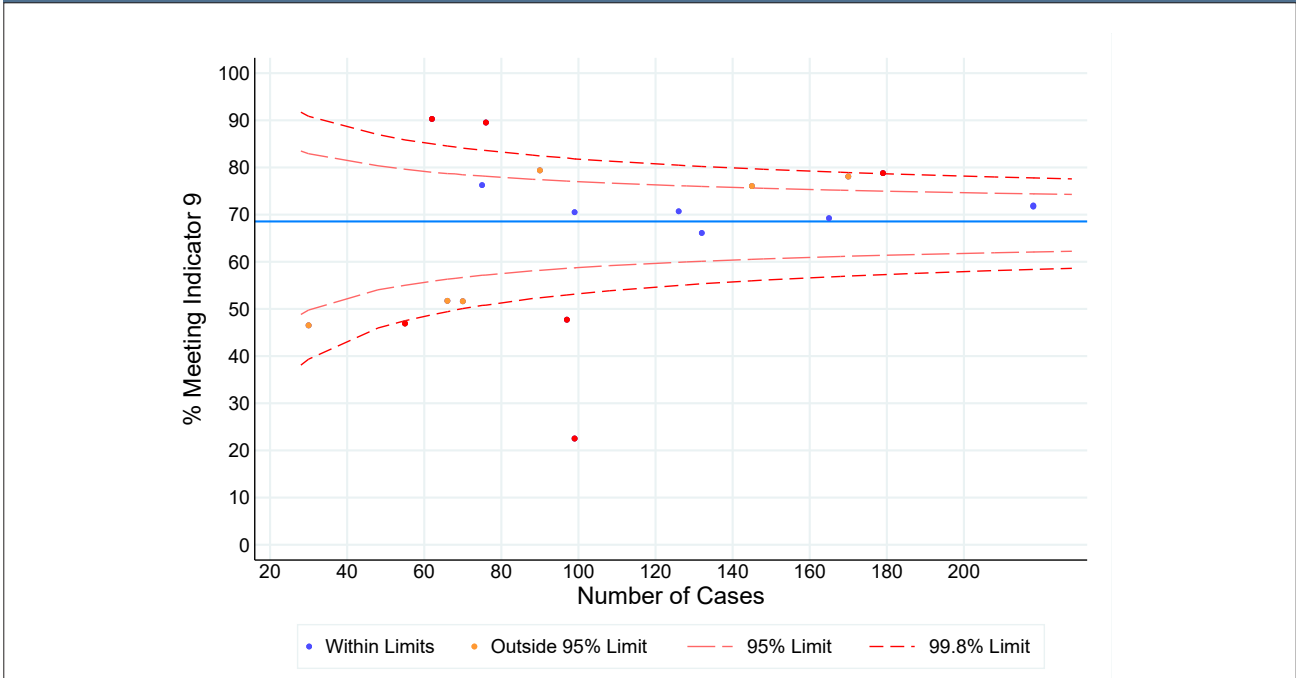
N = 476. Total cohort mean 62%.

Notes: Risk adjusted for patient sex, age and clinical stage. Surgical resection includes pneumonectomy, lobectomy, segmentectomy and wedge resection. The use of this funnel plot to identify potential outliers must be made with caution due to small numbers.

# EFFICIENT HEALTH CARE

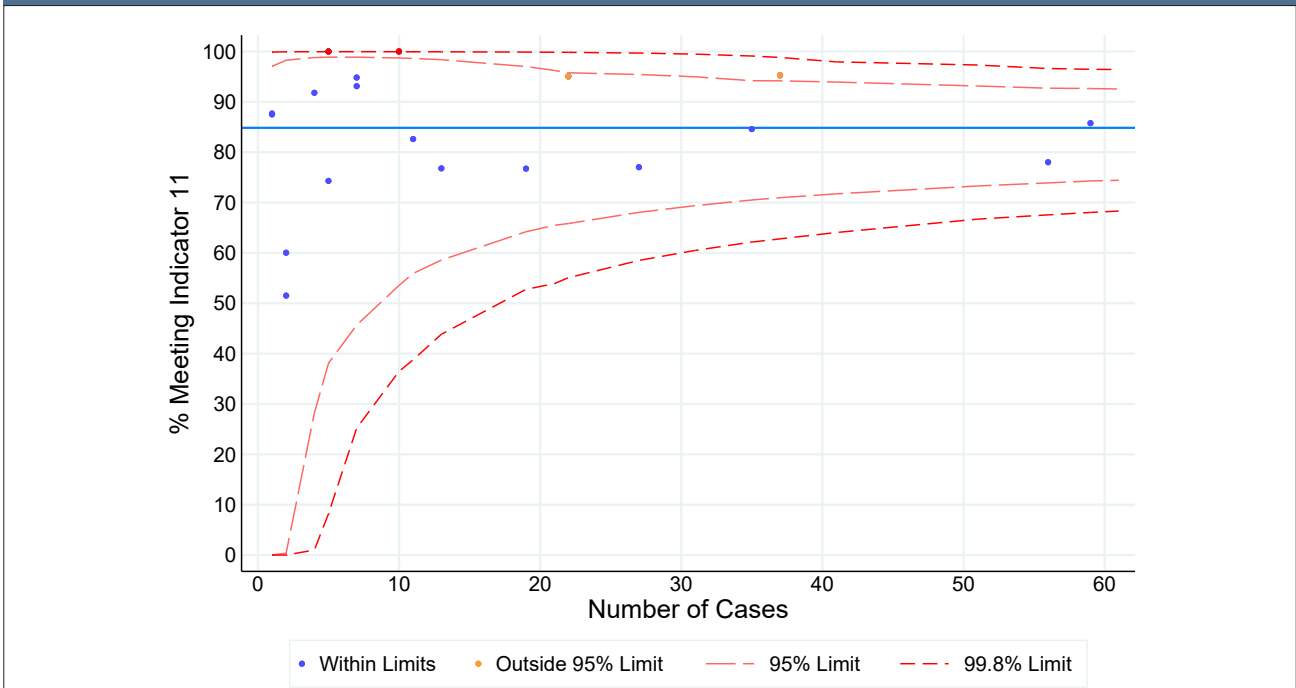
Efficient healthcare may be defined as, **'Optimal use of available resources to yield maximum health benefits'** [14]. Two indicators have been chosen to reflect efficiency of healthcare. First, the proportion of subjects for whom there is evidence of presentation to a multidisciplinary meeting, and second, the proportion of lung cancer resections for whom there is agreement between preoperative (clinical cTN) staging and post-operative (pathological pTN) staging.

**FIGURE 24: PROPORTION OF PATIENTS WITH PRESENTATION AT A LUNG CANCER MULTIDISCIPLINARY MEETING (MDM) DOCUMENTED (QUALITY INDICATOR 9)**



N = 2,172. Total cohort mean 69%.  
Notes: Risk adjusted for patient sex, age and clinical stage.

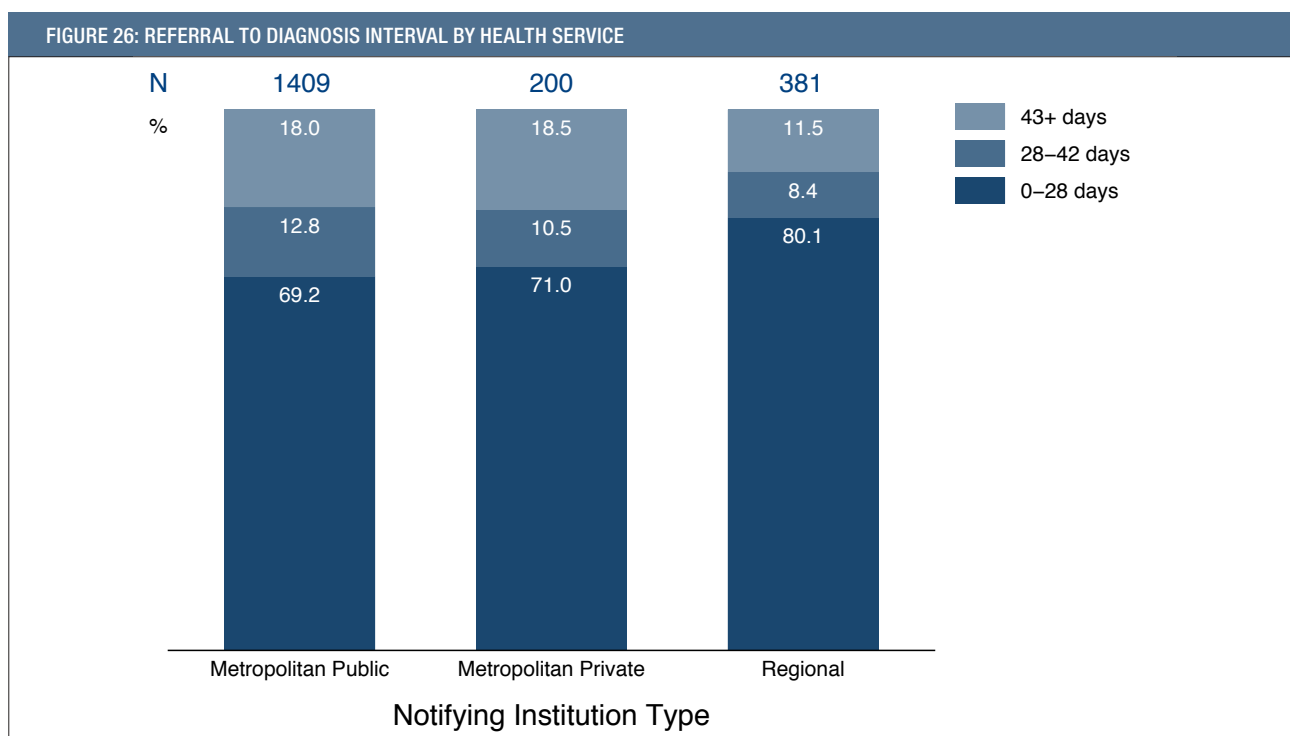
**FIGURE 25: PROPORTION OF PATIENTS WITH NSCLC WHO HAVE UNDERGONE A SURGICAL RESECTION AND CLINICAL STAGE (CTN) AGREES WITH PATHOLOGICAL STAGE (PTN) (QUALITY INDICATOR 11)**



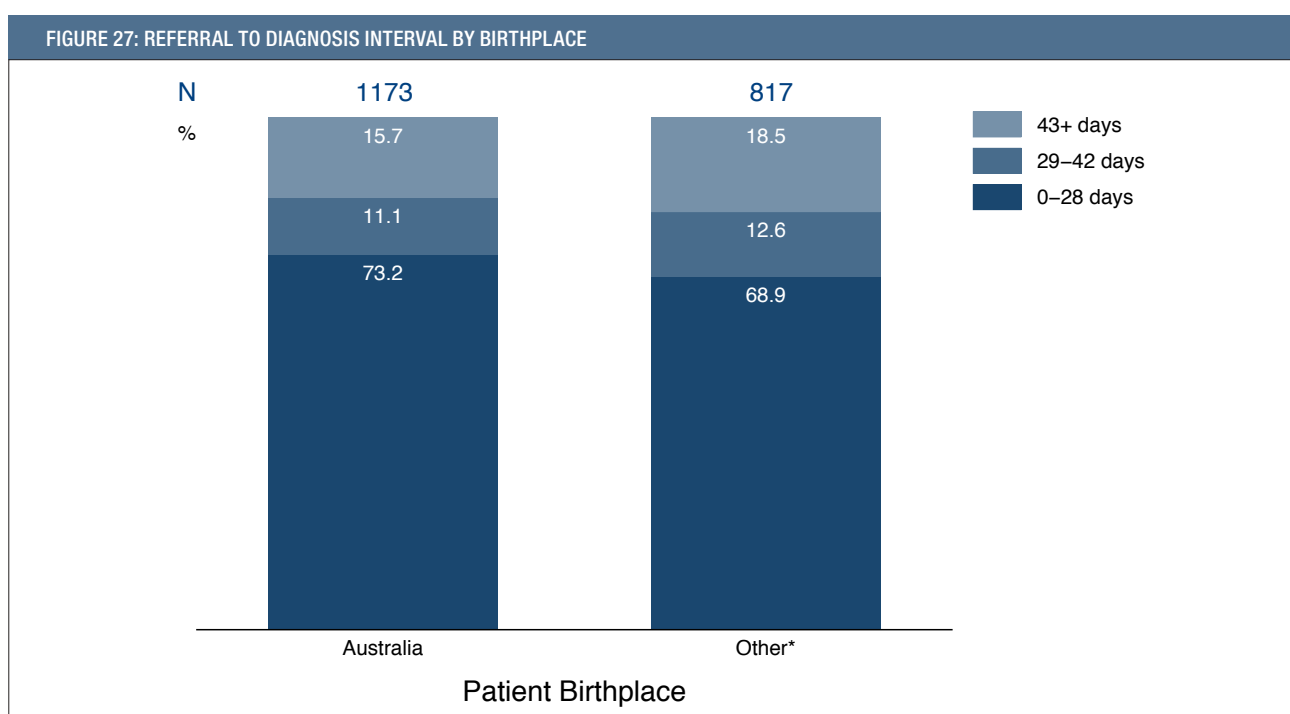
N = 323. Total cohort mean 85%.  
Notes: Risk adjusted for patient sex, age and clinical stage. The use of this funnel plot to identify potential outliers must be made with caution due to small numbers.

# EQUITABLE HEALTH CARE

Equitable healthcare may be defined as, ‘**Equal distribution of healthcare and its benefits, regardless of gender, ethnicity, geographic location or socio-economic status**’ [14].



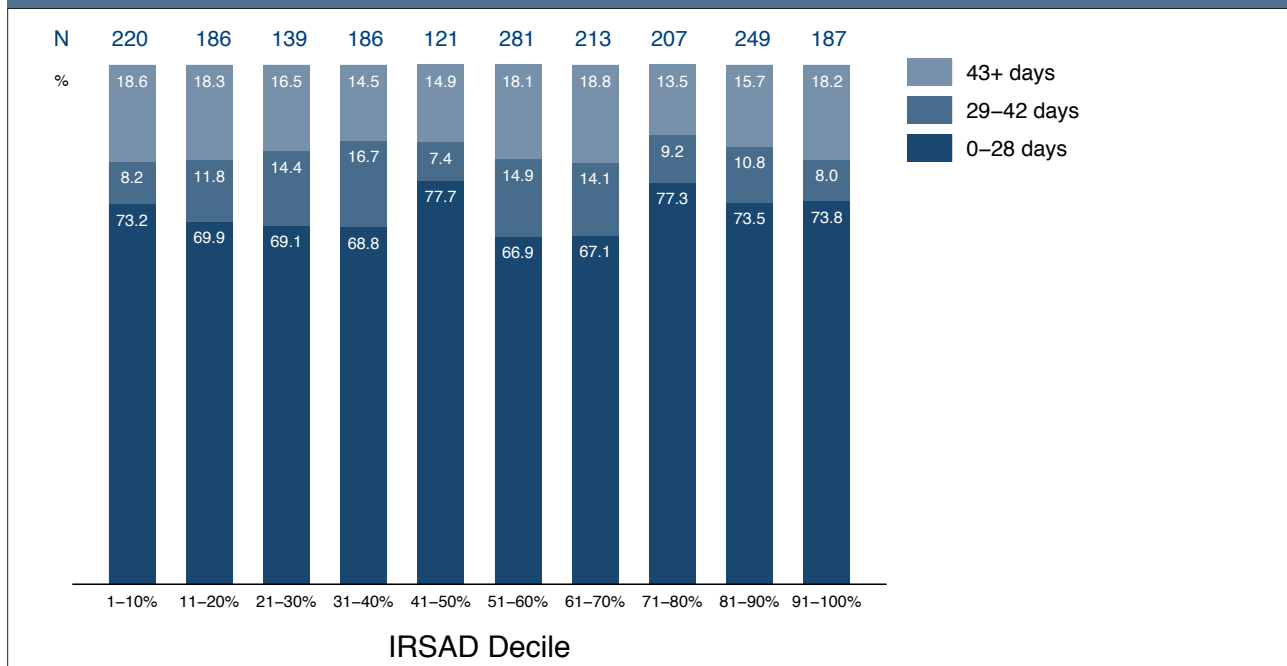
Notes: Pearson's chi-squared test: p-value = 0.001



Notes: Pearson's chi-squared test: p-value = 0.11.

\*Other includes 13 patients with unknown country of birth

FIGURE 28: REFERRAL TO DIAGNOSIS INTERVAL BY SOCIO-ECONOMIC STATUS



Notes: Pearson's chi-squared test: p-value = 0.16  
 IRSAD 1-10% denotes most socio-economically disadvantaged / least advantaged  
 IRSAD 91-10% denotes most socio-economically advantaged / least disadvantaged

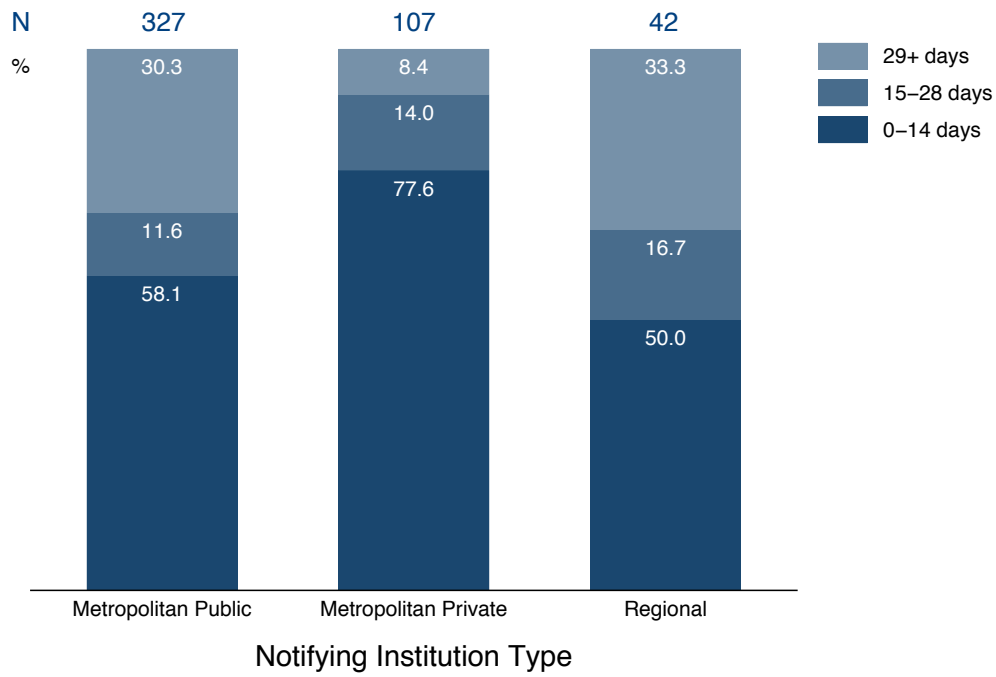
There was not a significant difference in the time interval from referral to diagnosis by socio-economic status, with the time from referral to diagnosis interval for patients in 2018 at similar levels for both least advantaged and least disadvantaged groups across all time intervals (Figure 28).

For the time interval from referral to diagnosis within 28 days, more Australian born patients had referral to diagnosis within 28 days when compared to non-Australian born patients, although this was not significant (Figure 27, 73.2% vs 68.9% p=0.11).

A comparison of time from referral to diagnosis by type of institution shows that Metropolitan public hospitals had a lower proportion of patients achieving rapid diagnosis (within 28 days from referral) when compared to Metropolitan Private and Regional hospitals, Figure 26 (69.2 vs 71.0 and 80.0, p=.001) and Metropolitan public and Metropolitan private hospitals had a higher proportion of patients with delayed diagnosis (more than 28 days following referral) when compared with Regional hospitals (18.0 and 18.5 vs 11.5, (p=.001), Figure 26.

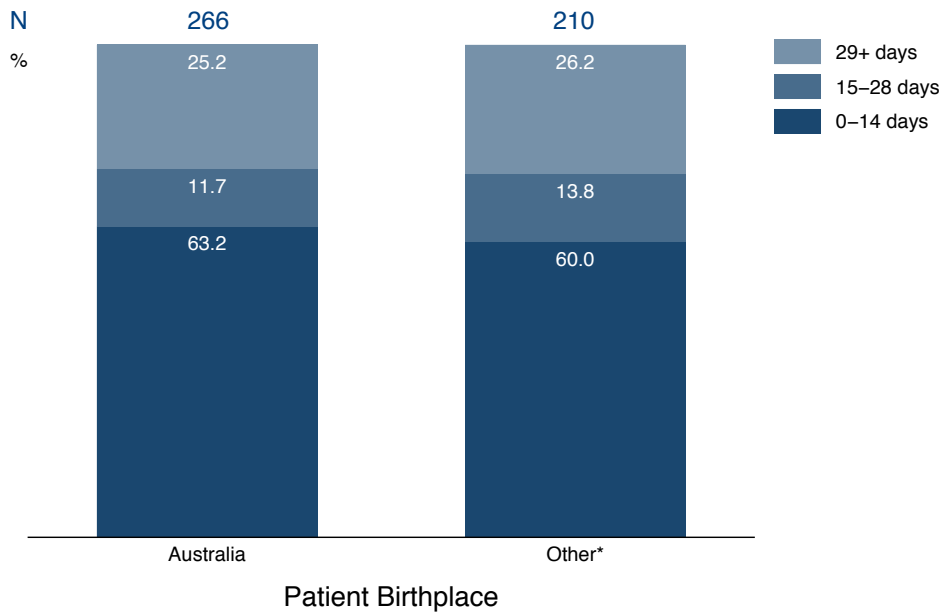


FIGURE 29 DIAGNOSIS TO SURGICAL RESECTION INTERVAL BY HEALTH SERVICE



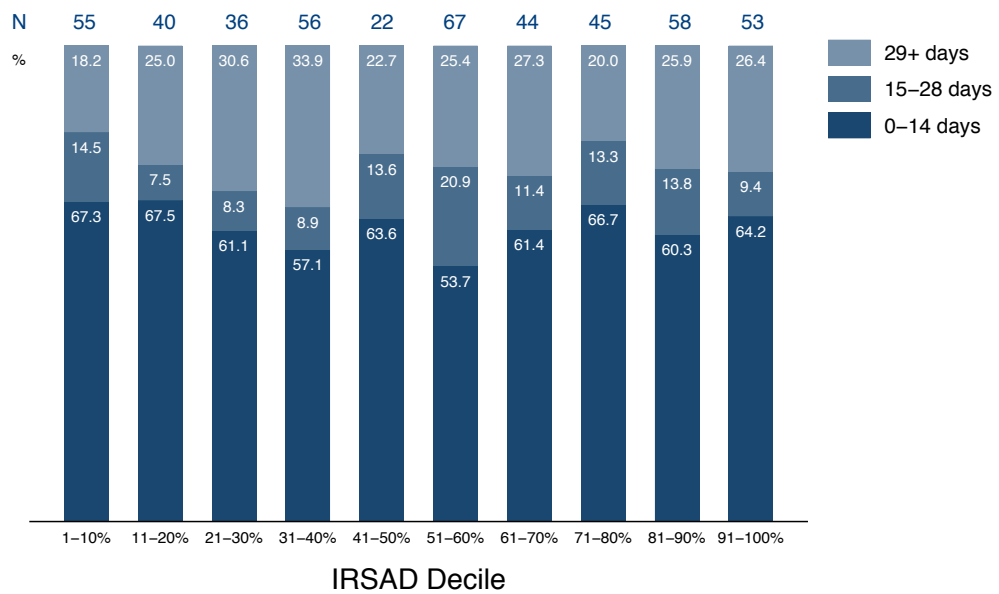
Notes: Pearson's chi-squared test: p-value = 0.16

FIGURE 30: DIAGNOSIS TO SURGICAL RESECTION INTERVAL BY BIRTHPLACE



Notes: Pearson's chi-squared test: p-value = 0.72  
 \*Other includes 13 patients with unknown country of birth

FIGURE 31: DIAGNOSIS TO SURGICAL RESECTION INTERVAL BY SOCIO-ECONOMIC STATUS



Notes: Pearson's chi-squared test: p-value = 0.86  
 IRSAD 1-10% denotes most socio-economically disadvantaged / least advantaged  
 IRSAD 91-10% denotes most socio-economically advantaged / least disadvantaged  
 One patient with unknown IRSAD were excluded

A higher proportion of patients from private institutions were resected within 14 days of referral (77.6%), compared with patients from metropolitan public or regional institutions (58.1%, 50% respectively), although the results were not statistically significant (p = 0.16), Figure 29.

The timeliness of surgical resection for patients in 2018 by patient ethnicity was not significantly different (Australia 63.2%, Other 60%, p = 0.72), Figure 30.

The time interval by socio-economic status indicates patients in the higher decile (least advantaged) showed similar results to those within the least disadvantaged, for resections within 0-14 days of referral (67.3% vs 64.2%, p = 0.86, Figure 31).

“Monitoring variation in healthcare is known to support best practice and improve quality of care. Clinical registries are increasingly recognised as credible, effective and feasible tools to measure variation and drive quality improvement at the national and jurisdictional health system levels. The School of Public Health and Preventive Medicine has extensive experience in the establishment and maintenance of such registries, providing the impetus to drive quality improvements and stimulate research in real-world populations. Thus the VLCR as a CQR is an invaluable resource for clinicians and health service researchers around Australia. We’re pleased to provide the 2018 Report.”

**PROFESSOR JOHN ZALCBERG  
HEAD, CANCER REGISTRY PROGRAM  
VLCR ACADEMIC LEAD.**

# APPENDICES

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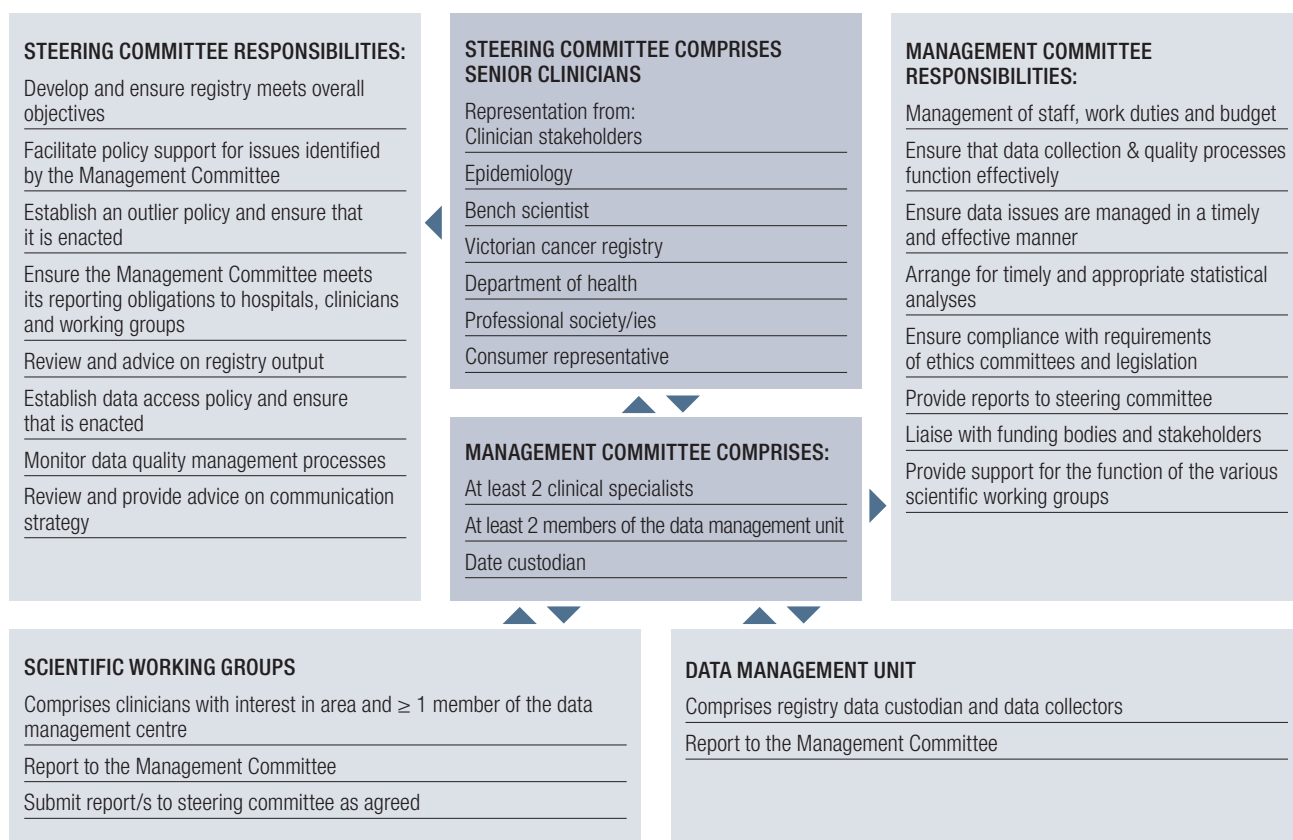
**APPENDIX C: VLCR STEERING COMMITTEE MEMBERSHIP IN 2018**

Name	Organisation and Title
Professor Susannah Ahern	Head, Registry Science and Research, Monash University.
Dr Nicola Atkin	Palliative Care Physician, Peter MacCallum Cancer Centre.
Professor David Ball	Deputy Director, Radiation Oncology & Cancer Imaging, Chair, Lung Service, Peter MacCallum Cancer Centre.
Dr Peter Briggs	Medical Oncologist, Monash Health.
Dr Lisa Briggs	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 Arul Earnest	Senior Biostatistician ,Registry Sciences Unit.
Professor Sue Evans	Director, Victorian Cancer Registry, Melbourne.
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	Professor of Epidemiology and Preventive Medicine, Monash University.
Professor Jeremy Millar	Deputy Chair, Cancer Council Australia. Research Director, Radiation Oncology, 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.
Dr Inger Olesen	Medical Oncologist, Geelong Hospital.
Associate Professor Gary Richardson	Director of Oncology Clinics Victoria, Director of Cabrini Academic Haematology & Oncology Services.
Associate Professor Rob Stirling (Chair)	Coordinating Principal Investigator and Steering Group Chairman, Victorian Lung Cancer Registry. Consultant Physician, Department of Allergy Immunology & Respiratory Medicine, The Alfred Hospital.
Associate Professor Gavin Wright	Director of Surgical Oncology, St Vincent's Hospital Melbourne.
Professor John Zalberg	Tony Charlton Chair of Oncology, Alfred Health. Head, Cancer Research Program, School of Public Health and Preventive Medicine, Monash University.

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 E: CLINICAL QUALITY INDICATORS		
No.	Numerator	Denominator
Timeliness Indicators:		
1	Number of patients where time from referral date to diagnosis is $\leq 28$ 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 $\leq 14$ 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 $\leq 14$ 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 $\leq 42$ 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
Treatment Indicators		
13	Number of patients with NSCLC (clinical stage I, II) who have had surgical resection	Number of patients with NSCLC
14	Number of patients with NSCLC (clinical stage I or II) and resection with $\geq 5$ lymph nodes dissected	Number of patients with NSCLC (clinical stage I or II) who have undergone surgical resection
15	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
16	Number of patients with NSCLC who have had a surgical resection and died within 90 days of surgery.	Number of patients with NSCLC who have undergone surgical resection
17	Number of patients receiving anti-cancer treatment (surgery, radiotherapy, chemotherapy or biological therapy )	Number of patients in Registry
18	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)
19	Number of patients NSCLC (pathological stage II) receiving platinum based chemotherapy after resection	Number of patients with NSCLC (pathological stage II) who have undergone a surgical resection
20	Number of patients with lung cancer where time from chemotherapy start date to death date is $\leq 30$ days	Number of patients receiving chemotherapy
Palliative Care Indicator		
21	Number of patients with NSCLC (stage IV) referred to any palliative care services within 8 weeks of diagnosis	Number of patients with NSCLC (stage IV)

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 2017 who meet the indicator definition and have been entered into the VLCR.

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.

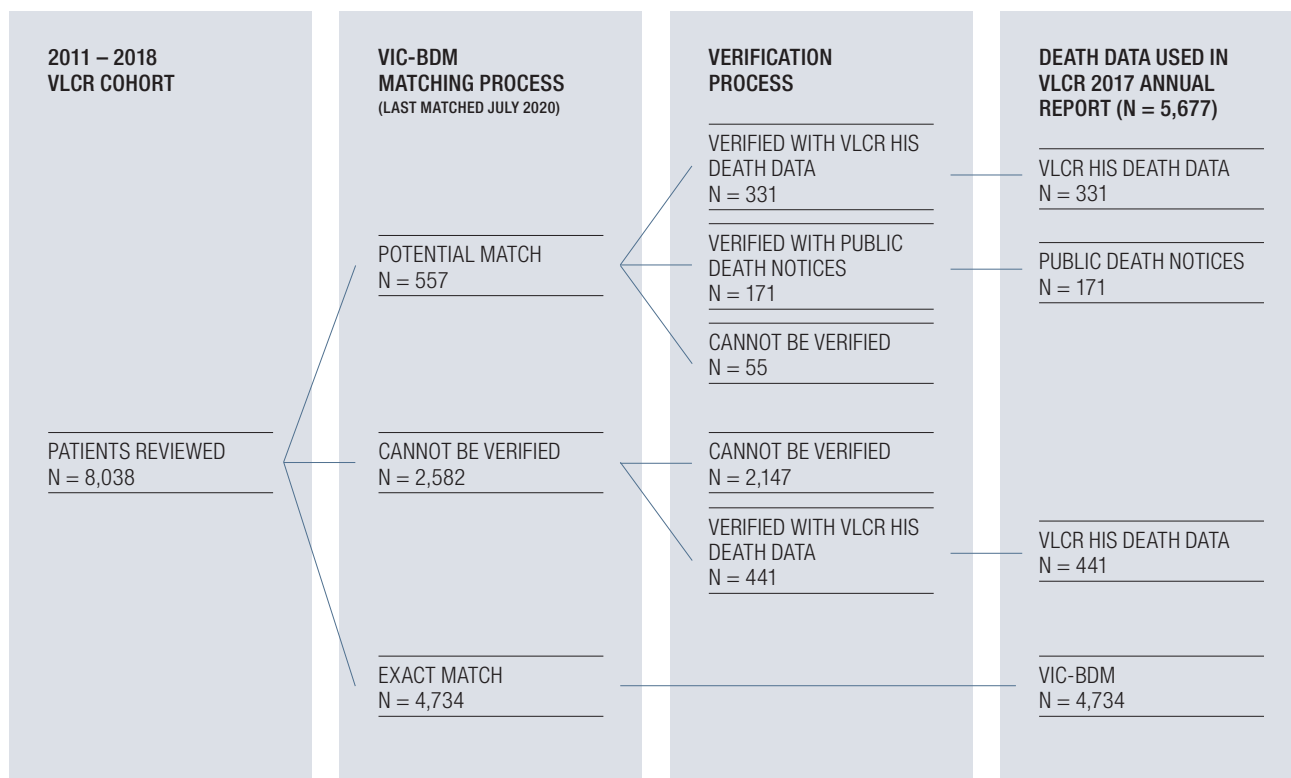
Case ascertainment for VLCR will occur via notification by participating site Health Information Systems of hospital discharges confirming ICD 10 coding identifying lung cancer as the principal reason for admission. Prevalence cases are discarded and incident cases are reviewed for inclusion and exclusion 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-AM 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 G: DEATH DATA SOURCES AND PROCESSES

Previous VLCR Annual reports have used death data from a single source, Victorian Births, Deaths and Marriages (Vic-BMD). The high number of “potential matches” prompted further investigation of other data sources to verify death dates: 1) VLCR database – Health Information Services (HIS) notification of a death that occurs following hospital admission, and 2) public death notice sources such as the Ryerson Index, Southern and Greater Metropolitan Cemeteries Trust. The “death data sources” flow chart shows how death data was obtained for use in this report.

DEATH DATA SOURCES



\* Vic-BDM: patients reviewed results: i) exact match (first name, last name and date of birth matched), ii) potential match (last name, date of birth matched), iii) Cannot be verified (first name, last name and date of birth not matched)

\*\* The VLCR receives death notification directly from site Health Information Services (HIS), directly uploaded to the VLCR database, or (infrequently) from patient’s next of kin (also updated into the VLCR database).



## APPENDIX H: REFERENCES

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## APPENDIX I: REGISTRY PUBLICATIONS, PRESENTATIONS AND SEMINARS

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