MONASH University

VICTORIAN LUNG CANCER REGISTRY

ANNUAL REPORT 2017

This publication was produced by the Victorian Lung Cancer Registry Suggested citation:

Stirling R, Martin C, Brand M, Zammit C, McNeil J, Evans S, Ahern S, Zalcberg J on behalf of the Victorian Lung Cancer Registry. The Victorian Lung Cancer Registry Annual Report, 2017. Monash University, Department of Epidemiology and Preventive Medicine, September 2017, Report No 4, pages 43.

Any enquiries or comments regarding this publication should be directed to:

Victorian Lung Cancer Registry
Monash University
Level 3 553 St Kilda Rd Melbourne VIC 3004
Phone: +61 3 9903 0206
Fax: +61 3 9903 0556
Email: med-cancerregistries@monash.edu

The contents of this report may not be published or used without permission.

CONTENTS

FOREWORD 2

EXECUTIVE SUMMARY 3

ANNUAL REPORT 2017 5

REGISTRY METHODOLOGY 6

REGISTRY SITE PARTICIPATION 7

SURVIVAL ANALYSIS 2011-2017 REGISTRATIONS 8

VLCR PATIENT CHARACTERSITICS 13

VLCR LUNG CANCER TYPES IN 2017 18

VLCR PATIENT PERFORMANCE STATUS IN 2017 19

CLINICAL QUALITY INDICATORS 20

SAFE HEALTH CARE 22

EFFECTIVE HEALTH CARE 24

PATIENT-CENTRED HEALTH CARE 26

TIMELY HEALTH CARE 28

EFFICIENT HEALTH CARE 30

EQUITABLE HEALTH CARE 32

APPENDICES 37

FOREWORD

It is with great pleasure that I present the Victorian Lung Cancer Registry (VLCR) 2017 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 2017 Annual Report includes outcome data from 14 participating health services, 65% of of all patients newly diagnosed with a primary lung cancer in Victoria, in the 2017 calendar year.

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

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.

The VLCR is managed by the Department of Epidemiology and Preventive Medicine, Monash University, which manages more than 20 clinical 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, Statisticians Arul Earnest and Cathy Martin and Data Analyst Breanna Pellegrini, 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

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 heath 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 2017 the VLCR population capture grew to 65% of all newly diagnosed cancer cases in Victoria, it is important to note that some indicators reported have low numbers and therefore, must be interpreted with caution.

The VLRC is a Clinical Quality Registry that collects "real world" observational data from participating health services.

KEY FINDINGS IN 2017:

Surgical resection: Post-operative mortality is low (1% mortality within 30 days), and the uptake of preoperative PET scanning prior to lung cancer resection is high (94%), with low variation between health services (80-100%).

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 remains low (27%), with significant variation between health services (0-62%). 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 2017 we report 38% of patients were referred to palliative care within 8 weeks of diagnosis, with a wide variation across health services (11-53%).

Timeliness of care: Referral to diagnosis within 28 days was recorded for 71% of patients, with wide variation between health services (55-81%). Time from diagnosis to surgical treatment within 14 days was recorded for 63% of patients with NSCLC, with wide variation (0-89%).

Timeliness of care by geographical region and SES status: A higher proportion of regional health services patients had a referral to diagnosis time within 28 days (75.5%) and less delays beyond 42 days (12.4%), compared with metropolitan public health services (69.6% and 20.1% respectively, p=0.03). 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 65% of patients diagnosed in 2017, with wide variation between institutions (29-82%). This shows a steady improvement in overall performance previously reported by the VLCR (2015, 54% and 2016, 58%).

Disease stage: Concordance between clinical stage (cTN) and post-operative stage (pTN) was high for the NSCLC cohort.

Survival analysis: Median survival time for males is 1.06 years after diagnosis and 1.47 years for females. Kaplan-Meier estimates show 54.2 survival at one year after diagnosis and 21.6 at 5 years after diagnosis. Survival rates are lower for patients diagnosed after 70 years of age and also lower for patients presenting at a later clinical stage.

Quality improvement is now a driving force in health care and is an essential aspect of service delivery at all levels. Put simiply, quality is everyone's business.

ANNUAL REPORT 2017

REGISTRY OVERVIEW AND REPORTING

Lung Cancer was the fourth most commonly diagnosed cancer in Australia in 2017 and the leading cause of cancer deaths in Australia 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 [7, 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 possibility of low dose screening may lead to earlier detection of lung cancer and new, more effective treatments will improve patient outcomes in the future. 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.

The Australian Commission on Safety and Quality in Health Care (ACSQHC) has confirmed clinical quality registries (CQRs) represent powerful tools for identifying and reducing variation in care through benchmarking and feedback on quality of care and clinical outcomes across multiple institutions [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 CQR that aims to assist health services in achieving optimal care deliver, according to accepted clinical guidelines. Data collected across multiple health services are used to reports key process and outcome measures for 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 23 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 2017 QI report to reflect key domains of care (safe, timely, patient-centred, efficient and equitable care). The VLCR Annual Report also includes aggregated, descriptive data for all patients in the Registry and survival curves.

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 2017 Annual Report is the third Annual Public Report.

DATA COLLECTION

In 2017, 15 health services (45 hospitals) participated in the Registry, of which seven were metropolitan public health services; three were metropolitan private health services and five regional health services. This comprised 1,643 eligible and consented new registry patients for 2017, bringing total VLCR recruitment to 6,029 patients since 2011.

The data contained in this document were extracted from the Victorian Lung Cancer Registry in November, 2018 for patients diagnosed with primary lung cancer from 1st January to 31st December, 2017. Data are collected from multiple sources, including passive data linkage and manual collection by trained data collectors from patient medical records.

The date of death used in this report was updated by Victoria Births Deaths and Marriages as at July 19th, 2019 (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 C).

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.

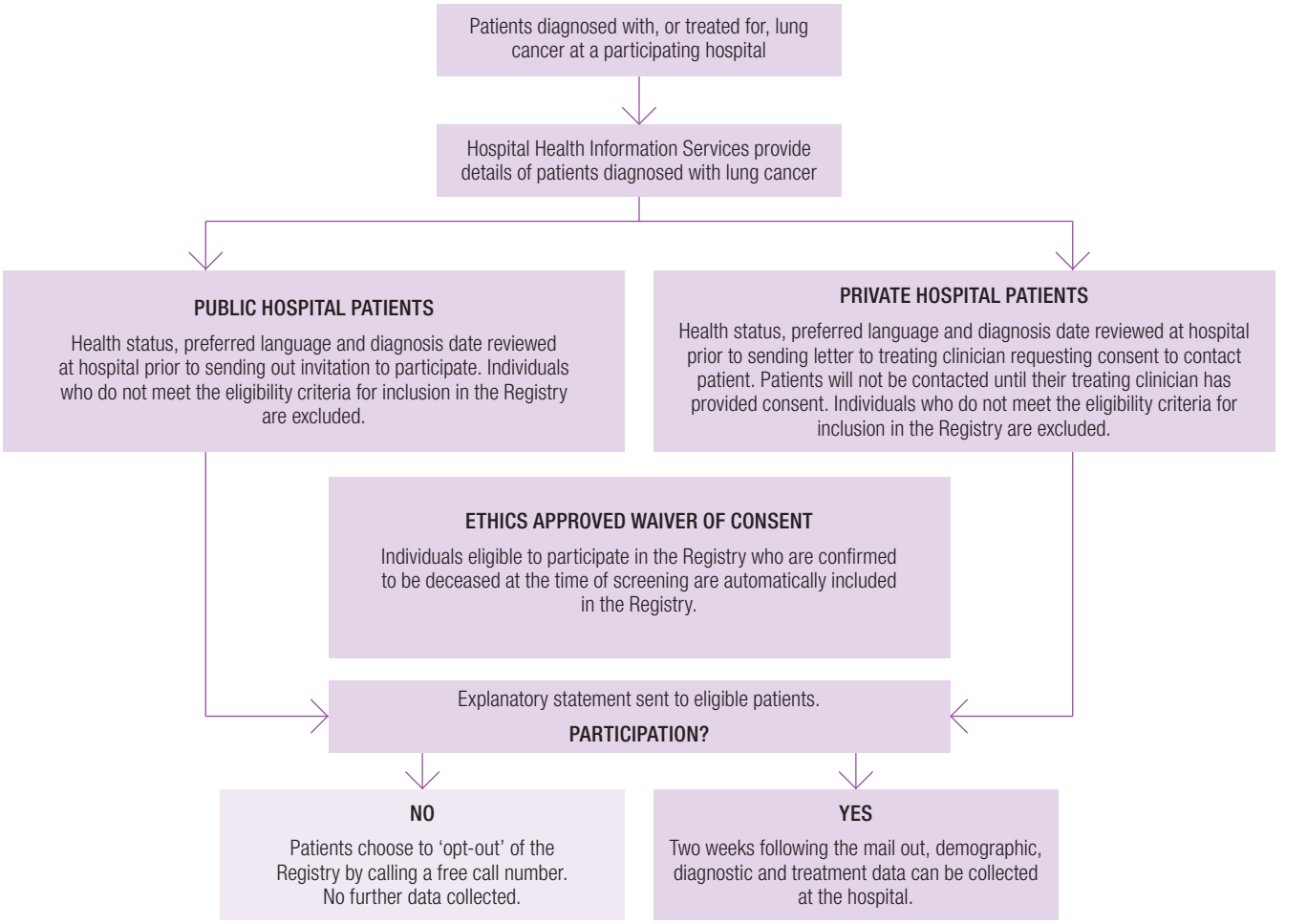
The VLCR data collection process can be described as follows.

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 the patient demographic data is imported into the Registry and key clinical information is collected from the medical record.

Stage 3: Collection of patient reported outcomes at 6 and 12 months post diagnosis has been temporarily suspended due to insufficient funding.

FIGURE 1: VLCR DATA COLLECTION PROCESS



REGISTRY SITE PARTICIPATION

REGISTRY SITE PARTICIPATION

Table 1 below shows the total number of participant registrations by year, since the Registry commenced in 2011 (N = 6,029).

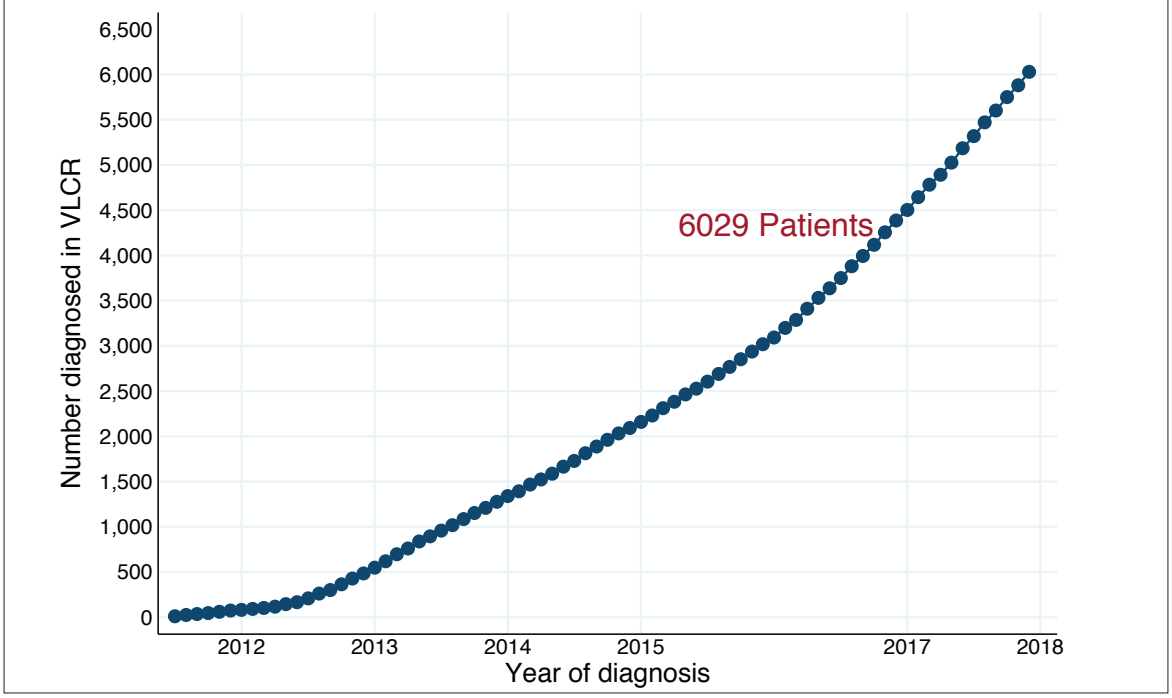
In 2017, 1,643 new lung cancer cases were captured by the VLCR (Table 1).

TABLE 1: VLCR PATIENT REGISTRATIONS BY YEAR

Diagnosis Year	Number
2011	76
2012	410
2013	792
2014	814
2015	927
2016	1,367
2017	1,643
Total	**6,029**

Figure 2 lists the cumulative patient registrations from 2011–2017.

FIGURE 2: CUMULATIVE VLCR REGISTRATIONS 2011–2017



Note: 6,029 VLCR patient registrations as at December 2018

SURVIVAL ANALYSIS 2011-2017 REGISTRATIONS

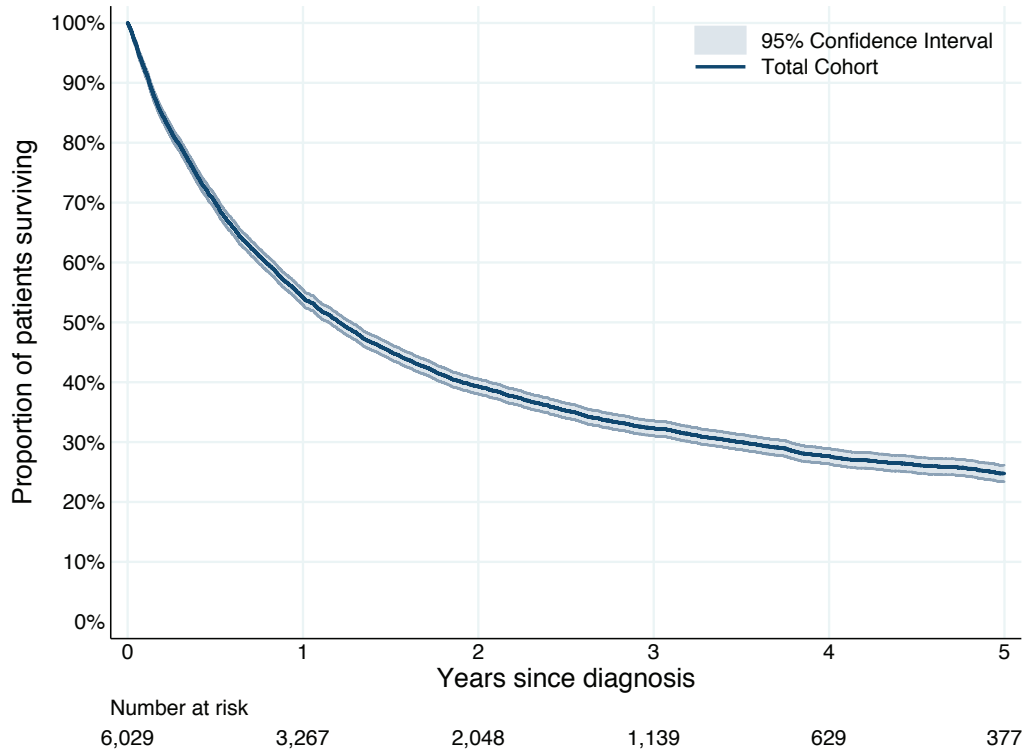
Kaplan-Meier estimates of survivorship using 2011-2017 VLCR registrations are presented in Figure 3 and Table 3 (n=6,029). Survivorship is also stratified by sex, age quartile groups and clinical stage in Figures 4-6. Survival rates are presented at annual time intervals from date of diagnosis with no 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 30th, 2019. 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. This process differs from previous reports where only Vic-BDM death dates had been used. Appendix G outlines the process described above, including the number of cases at each stage of matching and verification.

FIGURE 3: VLCR SURVIVAL ANALYSIS: 2011-2017 COHORT

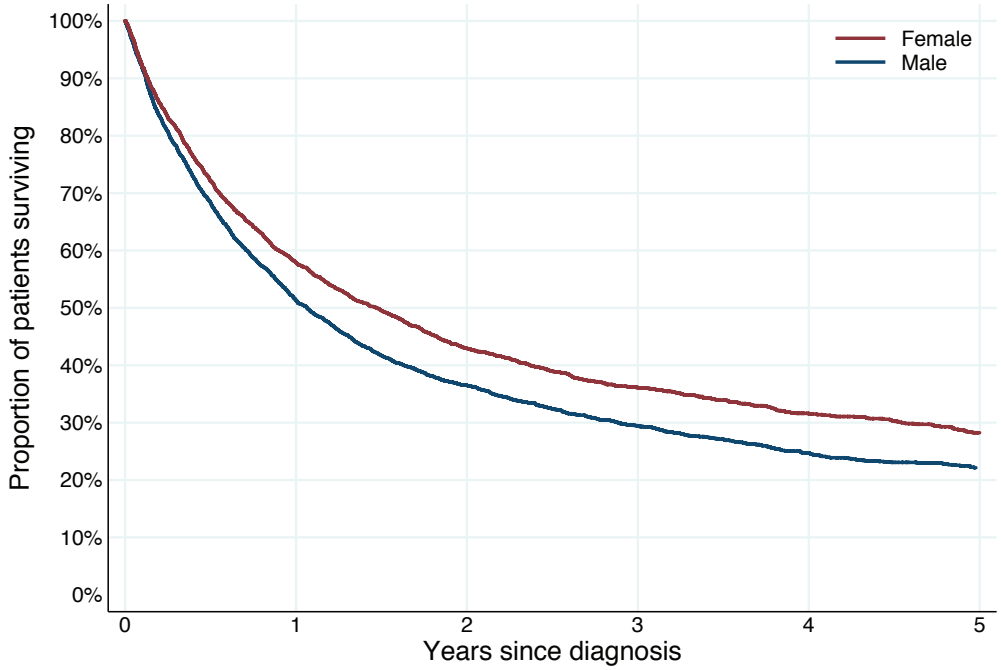


Based on 2011-2017 VLCR patient registrations, the median survival time is 1.15 years after diagnosis (Interquartile range: 0.37-4.92). The Kaplan-Meier estimates show 54.2% survival at one year after diagnosis and 21.6% at five years after diagnosis, Figure 3 and Table 3.

TABLE 2: VLCR 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
All patients	6,029	4,174	54.2% (52.9, 55.4)	39.3% (38.0, 40.5)	24.8% (23.4, 26.1)
Sex					
Males	3,426	2,470	51.4% (49.7, 53.0)	36.5% (34.9, 38.1)	22.1% (20.4, 23.9)
Females	2,603	1,704	57.9% (56.0, 59.8)	42.9% (41.0, 44.8)	28.3% (26.1, 30.5)
Age Group					
Less than 60 years	1,085	688	62.8% (59.8, 65.6)	45.3% (42.2, 48.2)	31.2% (27.9, 34.5)
60 to 69 years	1,762	1,175	56.9% (54.5, 59.1)	41.5% (39.2, 43.8)	27.7% (25.2, 30.2)
70 to 79 years	2,041	1,374	55.4% (53.2, 57.5)	41.5% (39.3, 43.6)	25.9% (23.4, 28.4)
80 years and older	1,141	937	39.8% (36.9, 42.6)	26.2% (23.6, 28.8)	12.0% (9.6, 14.7)
Clinical stage*					
Stage I	533	161	90.6% (87.8, 92.8)	81.6% (78.0, 84.6)	61.3% (55.4, 66.6)
Stage II	387	213	75.7% (71.1, 79.7)	59.4% (54.3, 64.1)	38.8% (32.9, 44.7)
Stage III	1,310	799	69.1% (66.5, 71.5)	49.7% (46.9, 52.4)	30.9% (27.7, 34.1)
Stage IV	2,294	2,010	33.5% (31.6, 35.5)	17.9% (16.4, 19.6)	8.6% (7.1, 10.1)
Not stated	1,503	989	54.3% (51.7, 56.8)	42.6% (40.0, 45.1)	27.6% (24.7, 30.5)

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

FIGURE 4: VLCR SURVIVAL ANALYSIS BY SEX: 2011 – 2017 COHORT

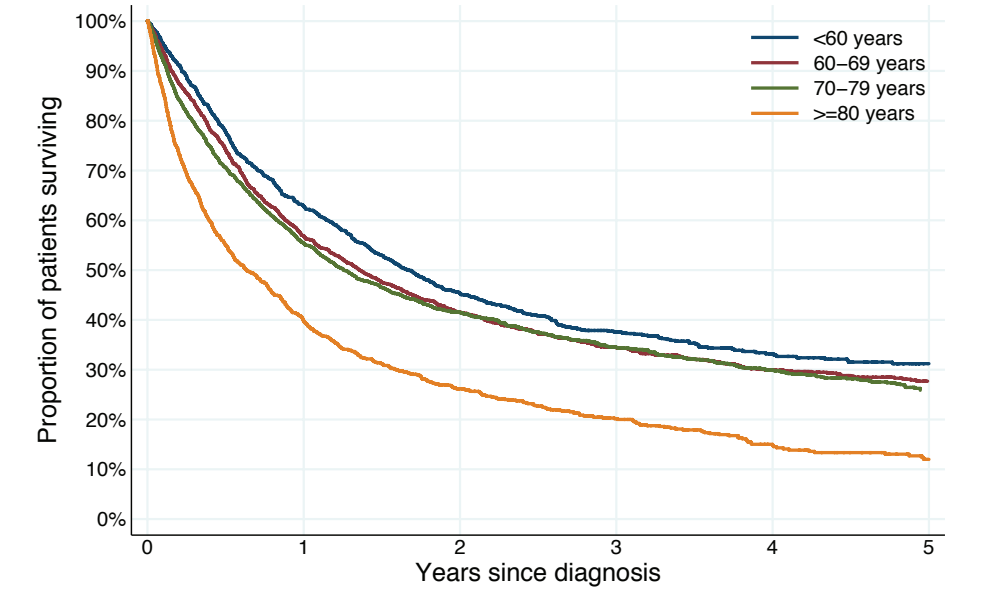


Number at risk by sex

Male	3,426	1,759	1,075	602	330	203
Female	2,603	1,508	973	537	299	174

Female survival was slightly higher at one year after diagnosis than male survival (Female: 57.9%; Male: 51.4%) and also at five years after diagnosis (Female: 28.3%, Male: 22.1%), Table 3.

FIGURE 5: VLCR SURVIVAL ANALYSIS BY AGE GROUP: 2011 – 2017 COHORT

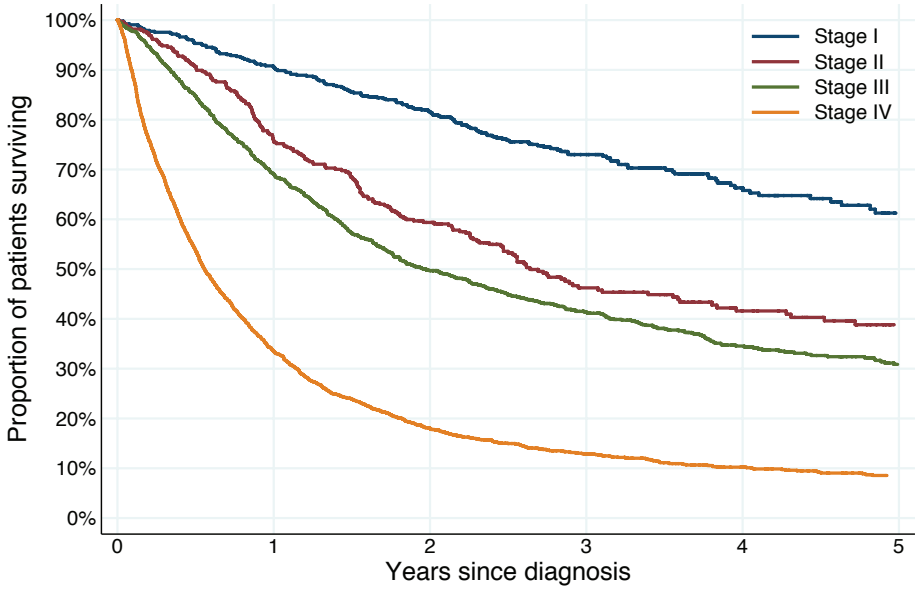


Number at risk by age

<60 years	1,085	681	433	246	132	80
60–69 years	1,762	1,002	624	367	212	132
70–79 years	2,040	1,130	734	392	221	133
>=80 years	1,141	454	257	134	64	32

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 39.8%, whereas survival at one year for those diagnosed before 60 years of age is 62.8%, Table 3 and Figure 5.

FIGURE 6: VLCR SURVIVAL ANALYSIS BY CLINICAL STAGE: 2011 – 2017 COHORT



Number at risk by clinical stage

Stage I	533	483	385	233	130	72
Stage II	387	293	198	105	68	39
Stage III	1,310	905	558	317	179	112
Stage IV	2,294	769	358	174	86	49

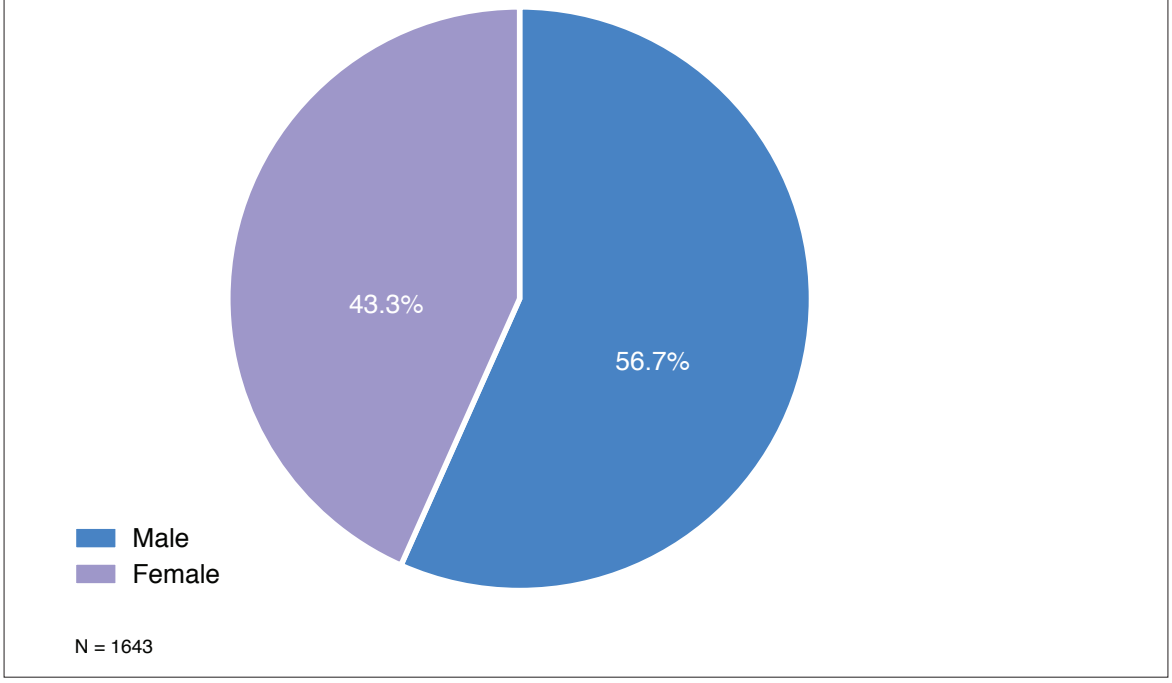
Crude survival rates are lower for patients presenting at a later clinical stage; survival at one year for Stage I patients is 90.6% and only 33.5% for Stage IV patients, Table 3 and Figure 6.

"The delays which I faced throughout my diagnosis and prior to the commencement of treatment, nearly cost me my life. Timeliness and care, needs to be made a priority, because when you are on borrowed time like I was, every single day matters."

VLCR PATIENT CHARACTERISTICS

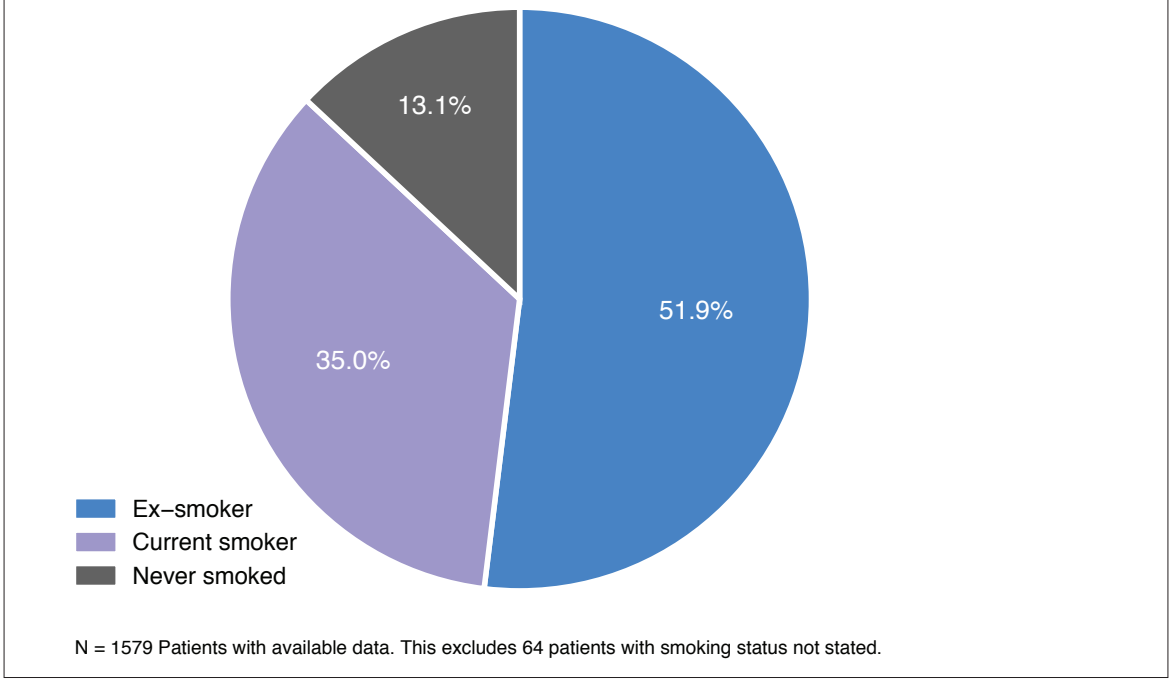
AGE, SEX, SMOKING STATUS, INDIGENOUS STATUS, COUNTRY OF BIRTH, PREFERRED LANGUAGE AND SOCIO-ECONOMIC PROFILE.

FIGURE 7: SEX



N = 1643

FIGURE 8: SMOKING STATUS



N = 1579 Patients with available data. This excludes 64 patients with smoking status not stated.

In the 2017 period there were a greater number of male than female participants, Figure 7 (56.7 vs 43.3%).

In 2017, approximately half (51.9%) of participants with available smoking status identified as an ex-smoker, 35.0% were current smokers and 13.1% had never smoked, Figure 8.

TABLE 3: LANGUAGE, BIRTHPLACE AND INDIGENOUS STATUS		
	Number	Percent
Region of Birth		
Australia	1,029	62.6%
England	77	4.7%
Italy	68	4.1%
Greece	58	3.5%
Scotland	27	1.6%
Poland	14	0.9%
Germany	21	1.3%
Malta	16	1.0%
Netherlands	25	1.5%
China	26	1.6%
Other	282	17.2%
Preferred Language		
English	1,501	91.4%
Greek	26	1.6%
Italian	20	1.2%
Mandarin	22	1.3%
Vietnamese	13	0.8%
Cantonese	7	0.4%
Russian	4	0.2%
Turkish	10	0.6%
Croatian	2	0.1%
Macedonian	2	0.1%
Other	36	2.2%
Indigenous Status		
Indigenous	13	0.8%
Non-Indigenous	1,630	99.2%
Total	**1,643**	**100%**

In 2017, 69% of VLCR participants were born in the Western pacific region, with the vast majority born in Australia (62.6%), Table 4.

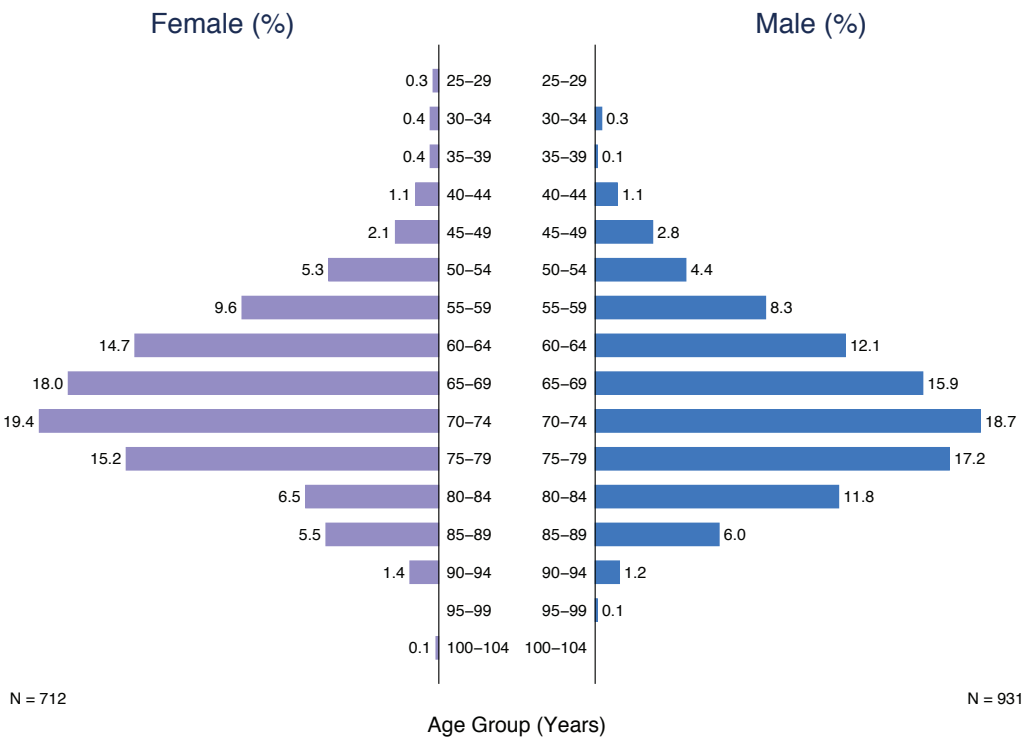
English was identified as the first language by 92% of participants and 0.8% of participants identified themselves as Indigenous Australians, Table 4.

ATSI identification is provided by participating site administrative data. Therefore, if ABTSI 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 4.

TABLE 4: PATIENT AGE GROUPING BY SEX			
	Female	Male	p–value (test)
Age	N = 712 (43.3%)	N = 931 (56.7%)	
Mean (Standard Deviation)	68.4 (10.8)	69.9 (10.7)	0.01 (Two sample t–test)

Male participants were on average, 1.5 years older than females at diagnosis, Table 5 (69.9 vs 68.4; p=0.01).

FIGURE 9: PATIENT AGE PROFILE BY SEX



The highest age at diagnosis incidence is in the 70-79 year age groups for both males and females (70.5%), with those diagnosed prior to 60 years of age representing 17% of male registrations and 19.8% of female registrations, Figure 9.

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 5: PATIENT SOCIO-ECONOMIC PROFILE		
SEIFA – IRSAD Decile	Number	Percent
1-10% (most disadvantaged)	144	8.76%
11-20%	149	9.07%
21-30%	96	5.84%
31-40%	139	8.46%
41-50%	100	6.09%
51-60%	188	11.44%
61-70%	152	9.25%
71-80%	205	12.48%
81-90%	237	14.42%
91-100% (most advantaged)	230	14.00%
Unknown	3	0.18%
Total	**1,643**	**100%**

Table 6 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 2016.

Of the 2016 VLCR patient cohort, the patient socio-economic profile appears dispersed, 39.9% lived in postal areas at diagnosis that were ranked in the top 20% (most advantaged areas). On the other socio-economic spectrum, 36.5% of the 2016 VLCR patients lived in areas ranked in the lowest 40% (most disadvantaged areas).

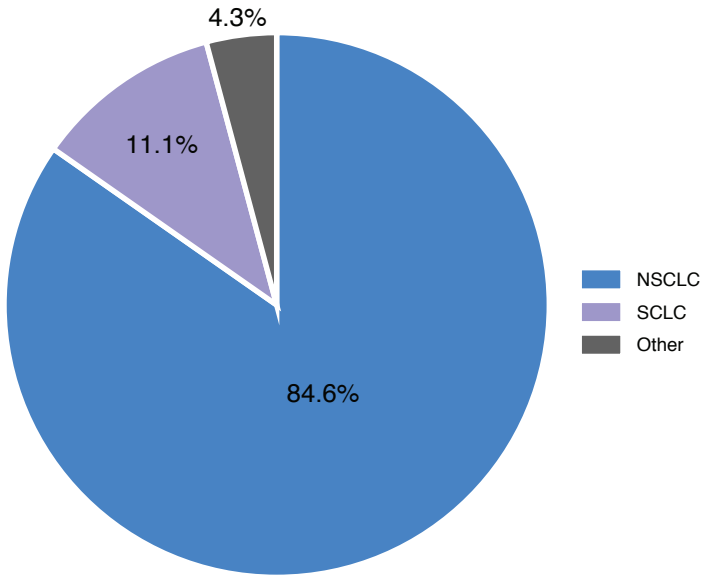
Providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions.

VLCR LUNG CANCER TYPES IN 2017

Cancer cell type is presented in Figure 10 below for the 2017 patient cohort with available data. Overall Non-Small Cell Lung Cancer (NSCLC) was the most frequent histology identified at 84.6%, Small Cell Lung Cancer (SCLC) comprised 11.1%, and 4.3% presented with other lung cancer types. Other lung cancer types include less commonly diagnosed cancers such as neuroendocrine cancers (n=23). Lung cancer type was not identifiable for 79 patients diagnosed in 2017. This includes 73 patients who had a clinical diagnosis (no histological test recorded) and 6 patients who had unknown morphology.

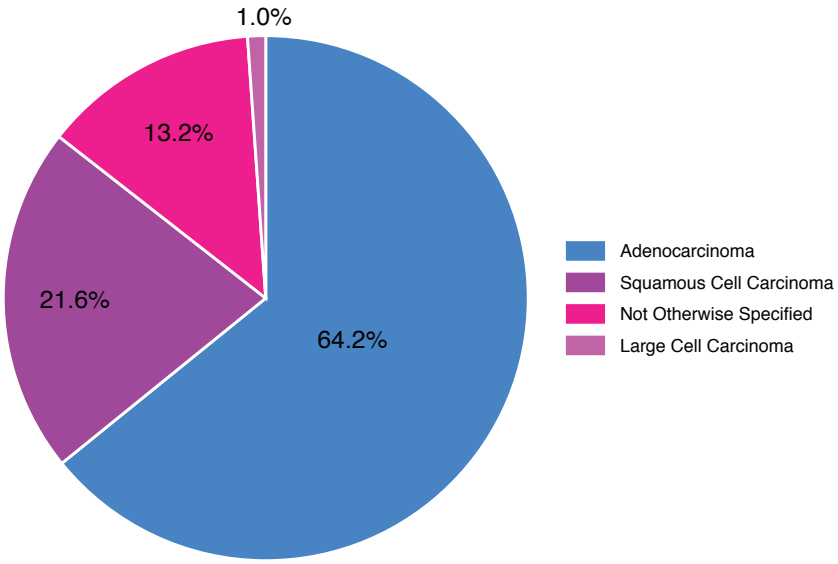
Of the 1,323 diagnosed with NSCLC in 2017, 64.2% had Adenocarcinoma, 21.6% had Squamous Cell Carcinoma, 1.0% had Large Cell Carcinoma and the remaining 13.2% were Not Otherwise Specified (NOS), Figure 11.

FIGURE 10: LUNG CANCER TYPE



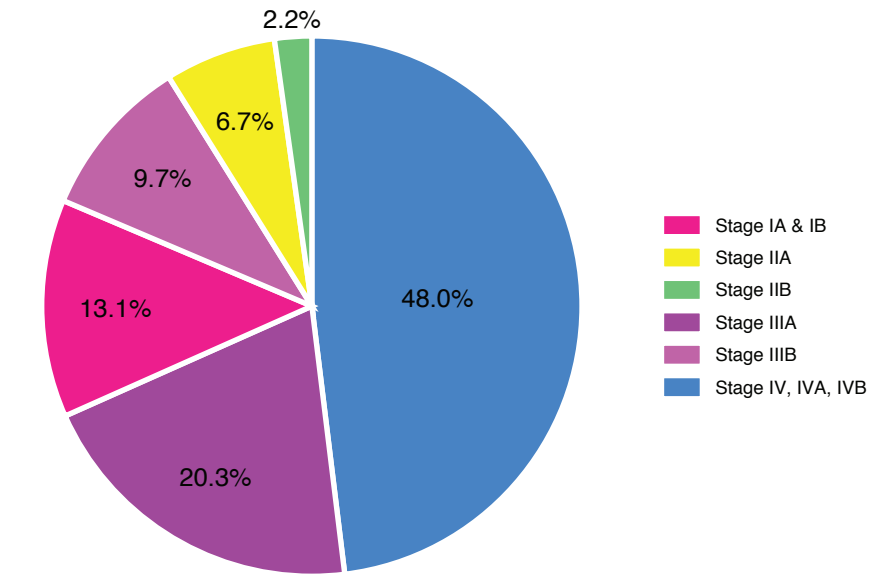
N = 1564 Patients with available data. This excludes 79 patients with lung cancer type not stated.

FIGURE 11: NSCLC TYPE



N = 1323 Patients with Non–small Cell Lung Cancer

FIGURE 12 :CLINICAL STAGING FOR NSCLC PATIENTS



N = 1013 Patients with Non–small Cell Lung Cancer and available clinical stage

Documentation of clinical stage was not recorded for 310 (23%) of the 1,323 NSCLC participants. Of the 1,013 patiants with NSCLC and documented clinical stage, the majority had advanced metastatic disease at presentation (Stage IV - 48%), while 31.7% had localised, early stage disease (Stage I-II), Figure 12.

VLCR PATIENT PERFORMANCE STATUS IN 2017

TABLE 6: PATIENT ECOG STATUS AT DIAGNOSIS

ECOG status at diagnosis	Number	Percent
0—Fully active, able to carry on all normal activity without restriction	402	24%
1—Restricted in physically strenuous activity but ambulatory and able to carry out light work	480	29%
2—Ambulatory and capable of all self-care but unable to carry out any work activities.	146	9%
3—Capable of only limited self-care, confined to bed or chair more than 50% of waking hours	75	5%
4—Completely disabled, not able to self-care, totally confined to bed or chair	16	1%
Unknown	524	32%
Total	**1,643**	**100%**

Documentation of performance status was unavailable for 32% of participants, 53%, had good performance status (ECOG 0–I) and 15% had poor performance status (ECOG ≥ 2), Table 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 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. 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.

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 13), 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 notifying institution group 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 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 institution's coloured dot, the smaller the volume, the further to the left its coloured 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 (red dashed lines) narrow. Each institution dot is coloured depending on where it falls compared to the 95% and 99.8% control limits. Green 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 SD of the benchmark.

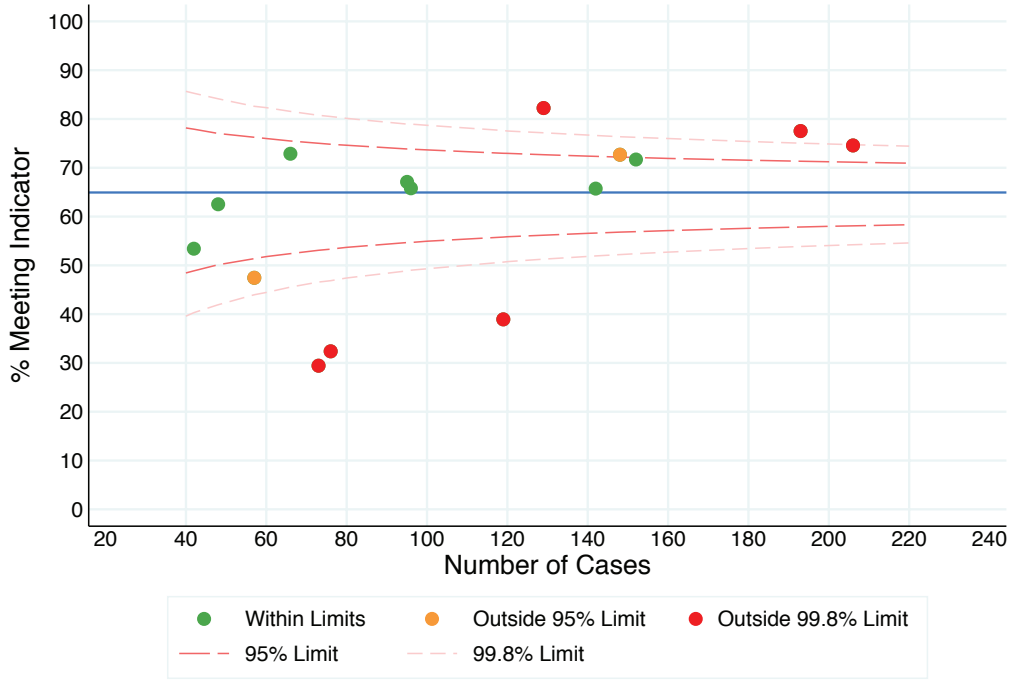
Special cause variation (aka assignable cause variation) is a shift in output caused by a specific factor such as environmental conditions or process input parameters. It can be accounted for directly and potentially removed, and is a measure of process control. Special cause variation is usually associated 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 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 13: FUNNEL PLOT EXAMPLE



Note: Risk adjusted for patient sex, age, birthplace 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** [10].

Appendix E lists data used to calculate each quality indicator. Indicators are presented in summary tables (Tables 8-17) with crude (non-adjusted) numbers, risk adjusted numbers and data completeness by institution group. Participating sites are de-identified and represented by numbers 1–14. Funnel plots risk adjusted for sex, age, birthplace and clinical stage are also provided for each indicator (Figures 14-23).

SAFE HEALTH CARE

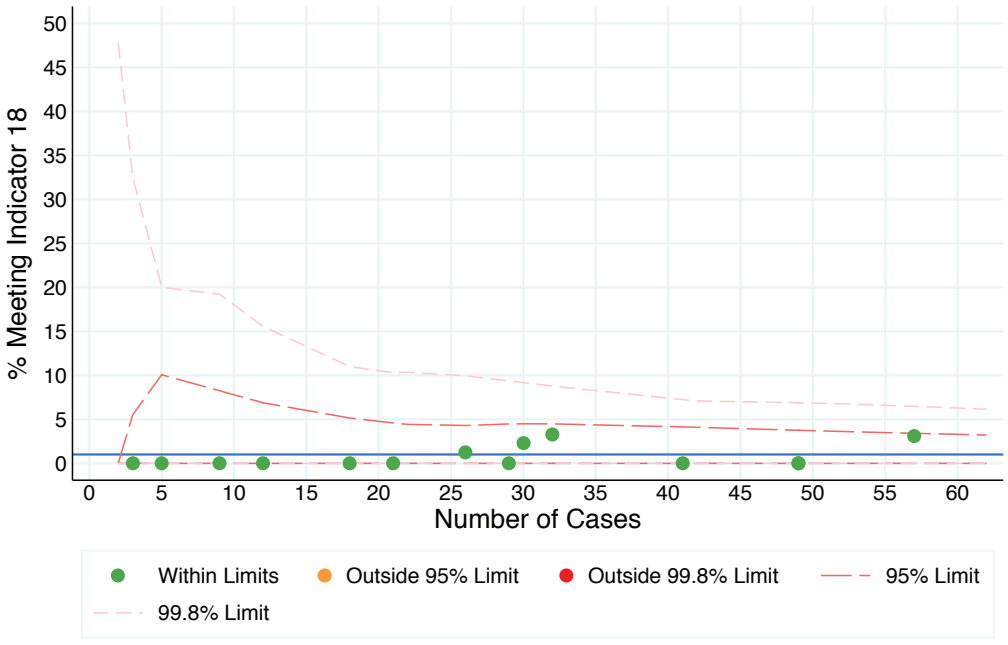
Safety in Healthcare may be defined as the, **'Degree to which health care processes avoid, prevent, and ameliorate adverse outcomes or injuries that stem from the process of health care itself'** [14].
Two indicators have been chosen to reflect patient safety. First, the mortality rate occurring within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

TABLE 7: PROPORTION OF PATIENTS WITH NSCLC WHO HAVE HAD A RESECTION AND DATE OF DEATH WITHIN 30 DAYS OF SURGERY (QUALITY INDICATOR 18)

Institution group	Numerator	Denominator	Meeting indicator (crude)	Meeting indicator (risk-adjusted)	Data completeness
1	1	26	4%	1%	100%
2	0	49	0%	0%	100%
3	1	32	3%	3%	100%
4	1	30	3%	2%	100%
5	0	49	0%	0%	100%
6	0	18	0%	0%	95%
7	0	21	0%	0%	100%
8	0	9	0%	0%	90%
9	0	5	0%	0%	100%
10	0	41	0%	0%	100%
11	0	5	0%	0%	100%
12	0	29	0%	0%	100%
13	0	12	0%	0%	92%
14	0	3	0%	0%	100%
15	1	57	2%	3%	100%
Total	**4**	**386**	**1%**		**100%**

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

FIGURE 14: PROPORTION OF PATIENTS WITH NSCLC WHO HAVE HAD A RESECTION AND DATE OF DEATH WITHIN 30 DAYS OF SURGERY (QUALITY INDICATOR 18)

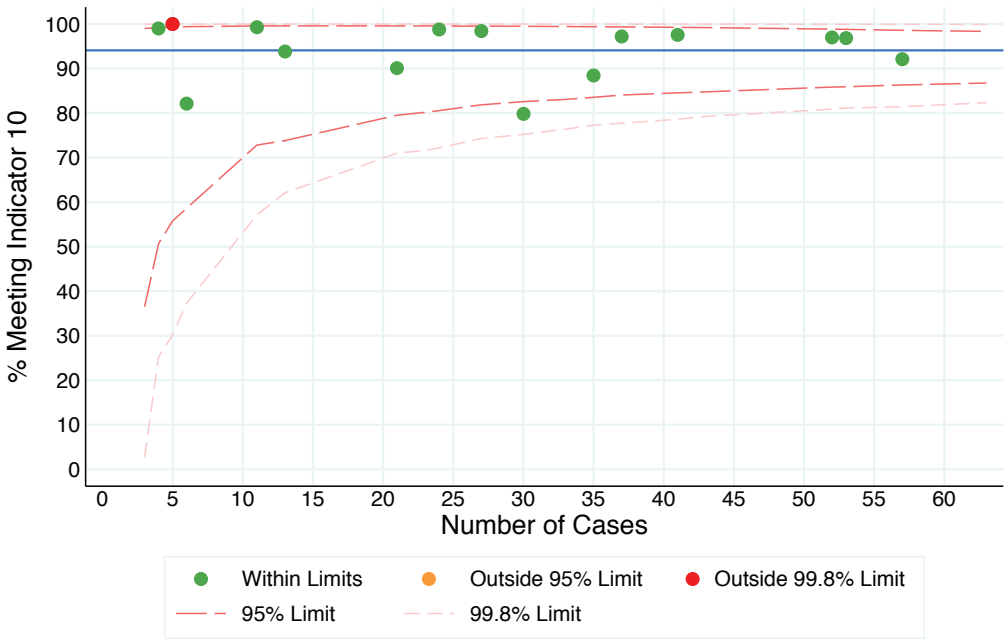


N = 386
Notes: Risk adjusted for patient sex, age, birthplace and clinical stage. The use of this funnel plot to identify potential outliers must be made with caution due to small numbers. In this funnel plot, sites with no deaths recorded are below the blue line (pooled average). Sites above the blue mean line have a death recorded within 30 days of resection. However, all sites are within 95% limit of the pooled average, suggesting common cause variability (refer page 20).

TABLE 8: PROPORTION OF PATIENTS UNDERGOING RESECTION WITH DOCUMENTED PET SCAN (QUALITY INDICATOR 10)					
Institution group	Numerator	Denominator	Meeting indicator (crude)	Meeting indicator (risk-adjusted)	Data completeness
1	26	27	96%	98%	100%
2	51	52	98%	97%	100%
3	36	37	97%	97%	100%
4	30	35	86%	88%	100%
5	52	53	98%	97%	100%
6	19	21	90%	90%	100%
7	24	24	100%	99%	100%
8	11	11	100%	99%	100%
9	5	5	100%	100%	100%
10	40	41	98%	98%	100%
11	5	6	83%	82%	100%
12	24	30	80%	80%	100%
13	12	13	92%	94%	100%
14	4	4	100%	99%	100%
15	53	57	93%	92%	100%
Total	**392**	**416**	**94%**		**100%**

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

FIGURE 15: PROPORTION OF PATIENTS UNDERGOING RESECTION WITH DOCUMENTED PET SCAN (QUALITY INDICATOR 10)



N = 416
Notes: Risk adjusted for patient sex, age, birthplace and clinical stage. The use of this funnel plot to identify potential outliers must be made with caution due to small numbers. PET scanning prior to curative treatment/surgical resection is recognised as a standard of care. 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 and to prevent inappropriate or futile surgery.

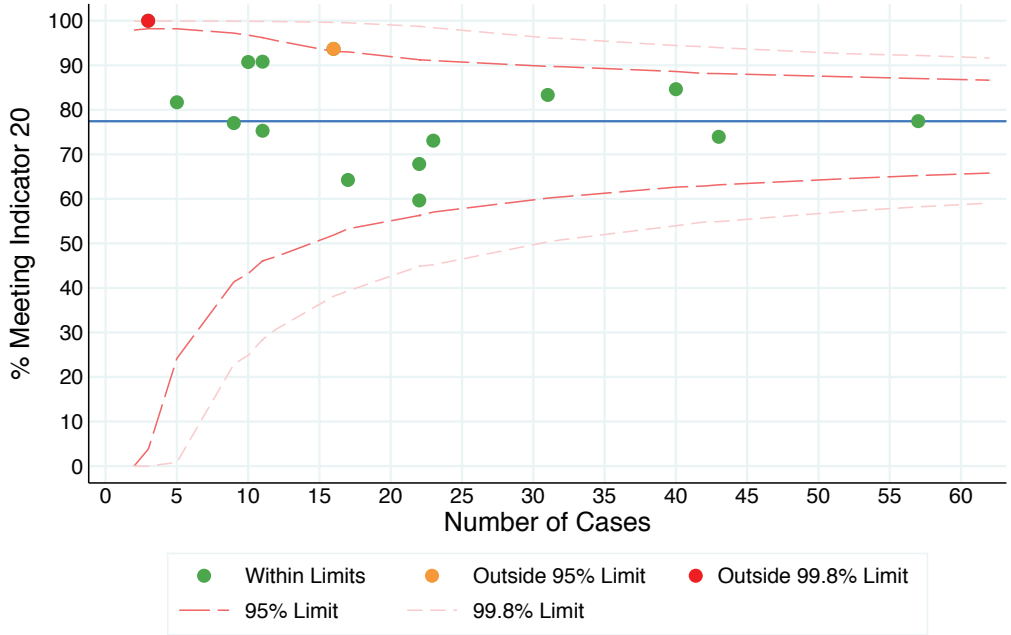
EFFECTIVE HEALTH CARE

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.

TABLE 9: PROPORTION OF PATIENTS WITH NSCLC (CLINICAL STAGE IIIB AND IV) WHO HAVE ECOG (0–1) WHO HAVE COMMENCED CHEMOTHERAPY (QUALITY INDICATOR 20)

Institution group	Numerator	Denominator	Meeting indicator (crude)	Meeting indicator (risk-adjusted)	Data completeness
1	17	23	74%	73%	88%
2	32	43	74%	74%	100%
3	10	17	59%	64%	100%
4	3	3	100%	100%	100%
5	7	9	78%	77%	100%
6	14	16	88%	94%	100%
7	15	22	68%	68%	100%
8	10	11	91%	91%	100%
9	35	40	88%	85%	100%
10	45	57	79%	77%	97%
11	9	10	90%	91%	83%
12	13	22	59%	60%	92%
13	4	5	80%	82%	100%
14	9	11	82%	75%	92%
15	25	31	81%	83%	100%
Total	**248**	**320**	**78%**		**97%**

FIGURE 16: PROPORTION OF PATIENTS WITH NSCLC (CLINICAL STAGE IIIB AND IV) WHO HAVE ECOG (0–1) WHO HAVE COMMENCED CHEMOTHERAPY (QUALITY INDICATOR 20)

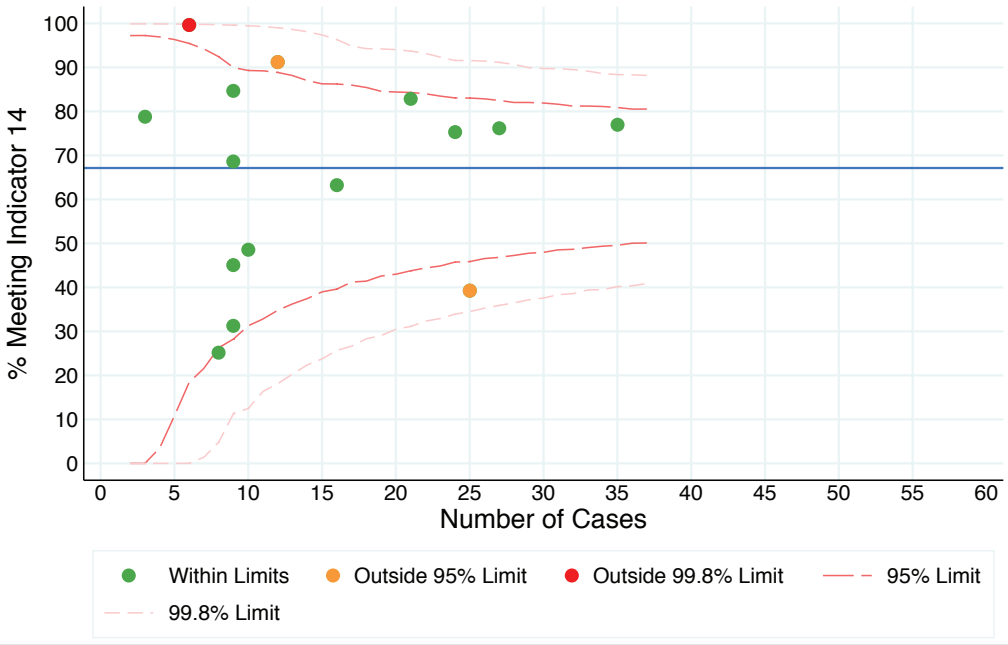


N = 320

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

TABLE 10: PROPORTION OF PATIENTS WITH NSCLC (CLINICAL STAGE I OR II) WHO HAVE HAD A SURGICAL RESECTION (QUALITY INDICATOR 14)					
Institution group	Numerator	Denominator	Meeting indicator (crude)	Meeting indicator (risk-adjusted)	Data completeness
1	9	25	36%	39%	100%
2	5	10	50%	49%	100%
3	19	21	90%	83%	100%
4	21	24	88%	75%	100%
5	6	9	67%	85%	100%
6	11	12	92%	91%	100%
7	10	16	63%	63%	100%
8	4	6	67%	100%	100%
9	2	8	25%	25%	100%
10	20	27	74%	76%	100%
11	1	3	33%	79%	100%
12	7	9	78%	69%	100%
13	4	9	44%	45%	100%
14	2	9	22%	31%	100%
15	30	35	86%	77%	100%
Total	**151**	**223**	**68%**		**100%**

FIGURE 17: PROPORTION OF PATIENTS WITH NSCLC (CLINICAL STAGE I OR II) WHO HAVE HAD A SURGICAL RESECTION (QUALITY INDICATOR 14)



N = 223
Notes: Risk adjusted for patient sex, age and birthplace. The use of this funnel plot to identify potential outliers must be made with caution due to small numbers and poor data completeness

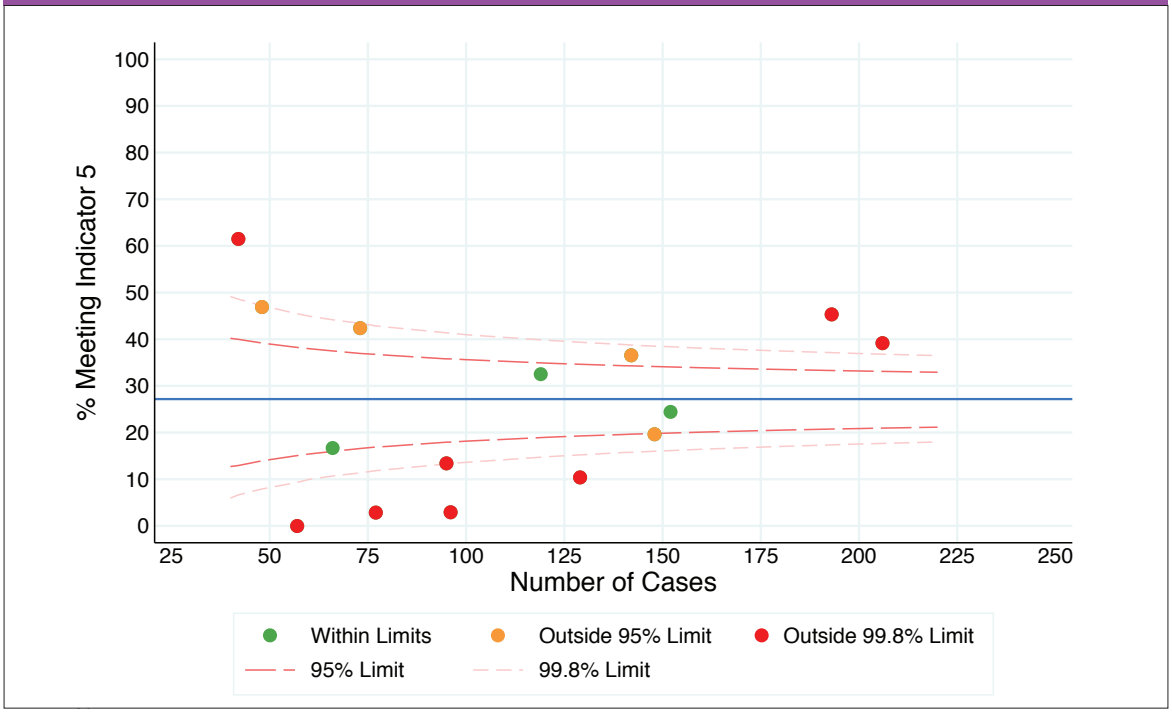
PATIENT-CENTRED HEALTH CARE

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.

TABLE 11: PROPORTION OF PATIENTS WITH DOCUMENTED SCREENING FOR SUPPORTIVE CARE (QUALITY INDICATOR 5)

Institution group	Numerator	Denominator	Meeting indicator (crude)	Meeting indicator (risk-adjusted)	Data completeness
1	30	148	20%	20%	100%
2	82	206	40%	39%	100%
3	3	96	3%	3%	100%
4	0	57	0%	0%	100%
5	32	119	27%	33%	100%
6	2	77	3%	3%	100%
7	56	142	39%	37%	100%
8	31	73	42%	42%	100%
9	14	95	15%	13%	100%
10	91	193	47%	45%	100%
11	25	42	60%	62%	100%
12	36	152	24%	24%	100%
13	22	48	46%	47%	100%
14	12	66	18%	17%	100%
15	13	129	10%	10%	100%
Total	**449**	**1,643**	**27%**		**100%**

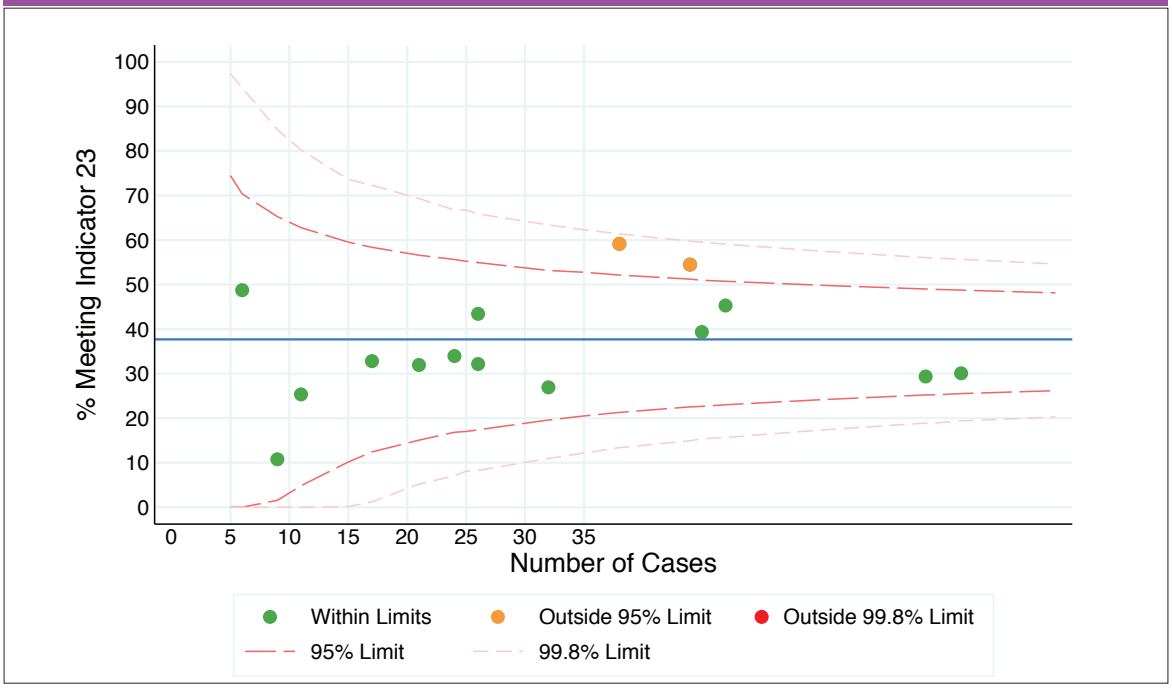
FIGURE 18: PROPORTION OF PATIENTS WITH DOCUMENTED SCREENING FOR SUPPORTIVE CARE (QUALITY INDICATOR 5)



N =1,643
Notes: Risk adjusted for patient sex, age, birthplace and clinical stage

TABLE 12: PROPORTION OF PATIENTS WITH NSCLC (STAGE IV) REFERRED TO ANY PALLIATIVE CARE SERVICES WITHIN 8 WEEKS OF DIAGNOSIS (QUALITY INDICATOR 23)					
Institution group	Numerator	Denominator	Meeting indicator (crude)	Meeting indicator (risk-adjusted)	Data completeness
1	21	38	59%	59%	100%
2	19	64	29%	29%	97%
3	9	24	34%	34%	92%
4	1	9	11%	11%	90%
5	12	26	43%	43%	100%
6	9	32	27%	27%	97%
7	21	47	45%	45%	98%
8	7	21	32%	32%	100%
9	17	45	39%	39%	100%
10	19	66	30%	30%	100%
11	3	11	25%	25%	92%
12	24	44	54%	54%	100%
13	3	6	49%	49%	100%
14	5	17	33%	33%	100%
15	9	26	32%	32%	96%
Total	**179**	**477**	**38%**		**98%**

FIGURE 19: PROPORTION OF PATIENTS WITH NSCLC (STAGE IV) REFERRED TO ANY PALLIATIVE CARE SERVICES WITHIN 8 WEEKS OF DIAGNOSIS (QUALITY INDICATOR 23)



N = 477
Notes: Risk adjusted for patient sex, age, birthplace and clinical stage. The use of this funnel plot to identify potential outliers must be made with caution due to small numbers.

TIMELY HEALTH CARE

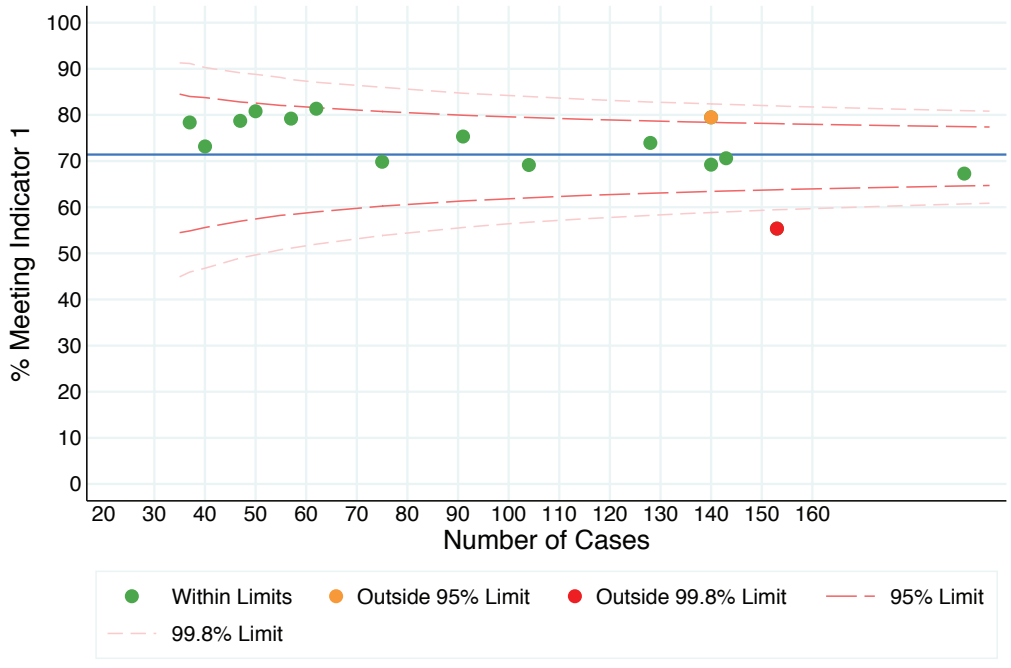
Timely healthcare may be defined as, **'Providing care within accepted time limits, after recognising the need for care. This includes the time interval to being seen by a doctor, and the time interval between identifying a need for specific tests and treatments and actually receiving the services'** [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.

TABLE 13: PROPORTION OF PATIENTS WHERE REFERRAL TO DIAGNOSIS DATE IS WITHIN 28 DAYS (QUALITY INDICATOR 1)

Institution group	Numerator	Denominator	Meeting indicator (crude)	Meeting indicator (risk-adjusted)	Data completeness
1	99	143	69%	71%	67%
2	87	153	57%	55%	74%
3	52	75	69%	70%	78%
4	27	37	73%	78%	65%
5	70	104	67%	69%	87%
6	47	57	82%	79%	74%
7	100	140	71%	69%	99%
8	41	50	82%	81%	68%
9	72	91	79%	75%	96%
10	128	190	67%	67%	98%
11	30	40	75%	73%	95%
12	115	140	82%	80%	92%
13	34	47	72%	79%	98%
14	51	62	82%	81%	94%
15	87	128	68%	74%	99%
Total	**1,040**	**1,457**	**71%**		**89%**

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

FIGURE 20: PROPORTION OF PATIENTS WHERE REFERRAL TO DIAGNOSIS DATE IS WITHIN 28 DAYS (QUALITY INDICATOR 1)

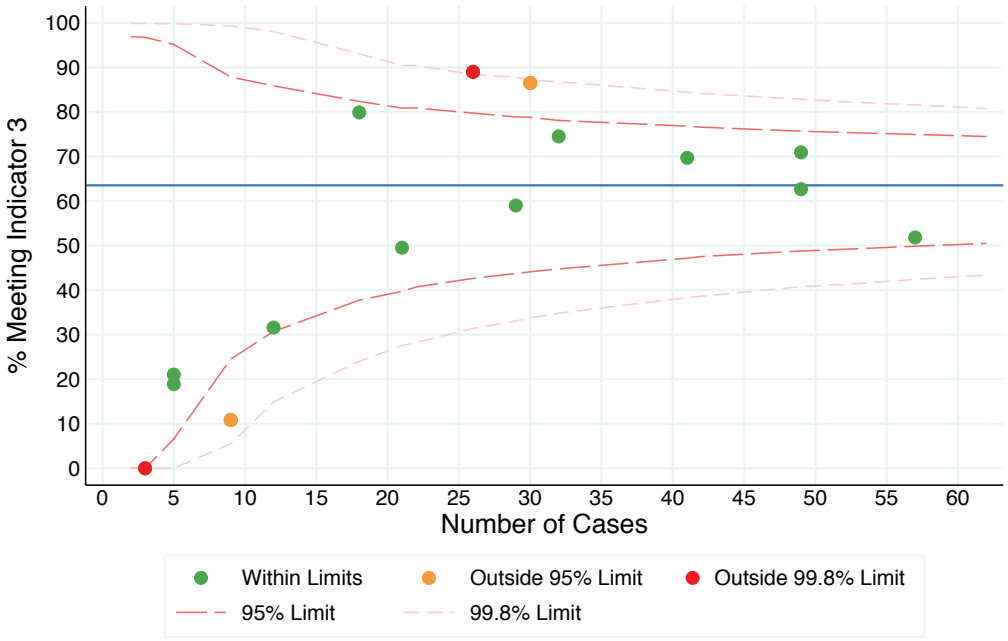


N = 1,457
Notes: Risk adjusted for patient sex, age, birthplace and clinical stage.

TABLE 14: PROPORTION OF PATIENTS WITH NSCLC WHERE TIME FROM DIAGNOSIS TO SURGICAL RESECTION IS WITHIN 14 DAYS (QUALITY INDICATOR 3)					
Institution group	Numerator	Denominator	Meeting indicator (crude)	Meeting indicator (risk-adjusted)	Data completeness
1	21	26	81%	89%	100%
2	34	49	69%	63%	100%
3	21	32	66%	75%	100%
4	25	30	83%	87%	100%
5	38	49	78%	71%	100%
6	14	18	78%	80%	95%
7	10	21	48%	50%	100%
8	1	9	11%	11%	90%
9	1	5	20%	21%	100%
10	28	41	68%	70%	100%
11	1	5	20%	19%	100%
12	17	29	59%	59%	100%
13	4	12	33%	32%	92%
14	0	3	0%	0%	100%
15	29	57	51%	52%	100%
Total	**244**	**386**	**63%**		**99%**

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

FIGURE 21: PROPORTION OF PATIENTS WITH NSCLC WHERE TIME FROM DIAGNOSIS TO SURGICAL RESECTION IS WITHIN 14 DAYS (QUALITY INDICATOR 3)



N = 386
Notes: Risk adjusted for patient sex, age, birthplace and clinical stage. The use of this funnel plot to identify potential outliers must be made with caution due to small numbers.

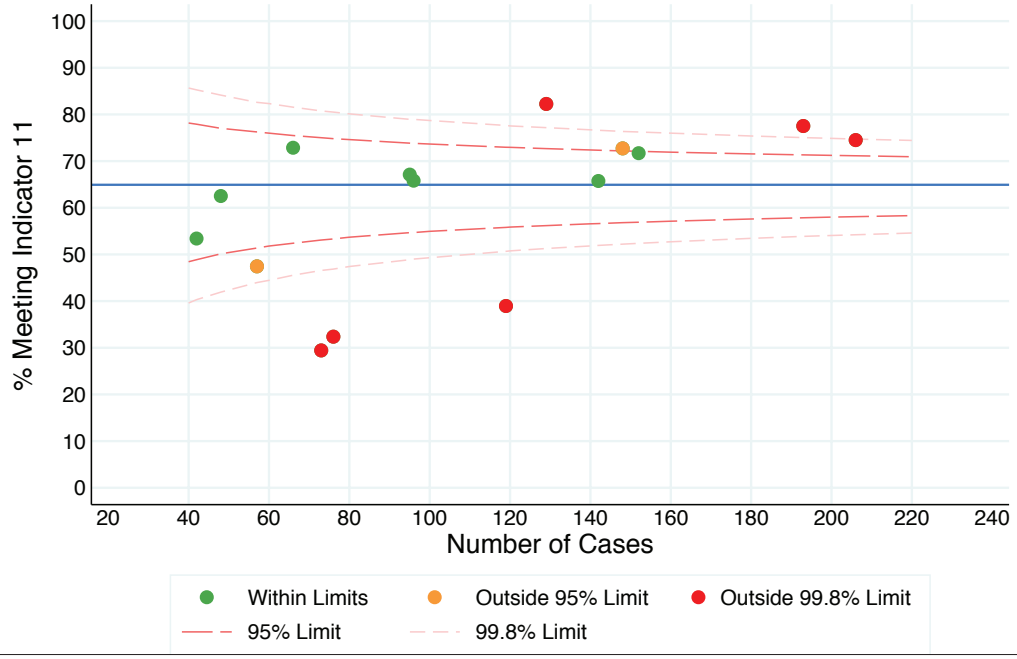
EFFICIENT HEALTH CARE

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.

TABLE 15: PROPORTION OF PATIENTS WITH PRESENTATION AT A LUNG CANCER MULTIDISCIPLINARY MEETING (MDM) DOCUMENTED (QUALITY INDICATOR 11)

Institution group	Numerator	Denominator	Meeting indicator (crude)	Meeting indicator (risk-adjusted)	Data completeness
1	112	148	76%	73%	100%
2	143	206	69%	75%	100%
3	70	96	73%	66%	100%
4	30	57	53%	47%	100%
5	39	119	33%	39%	100%
6	23	77	30%	32%	99%
7	97	142	68%	66%	100%
8	21	73	29%	29%	100%
9	64	95	67%	67%	100%
10	153	193	79%	78%	100%
11	21	42	50%	53%	100%
12	101	152	66%	72%	100%
13	32	48	67%	63%	100%
14	52	66	79%	73%	100%
15	116	129	90%	82%	100%
Total	**1,074**	**1,643**	**65%**		**100%**

FIGURE 22: PROPORTION OF PATIENTS WITH PRESENTATION AT A LUNG CANCER MULTIDISCIPLINARY MEETING (MDM) DOCUMENTED (QUALITY INDICATOR 11)

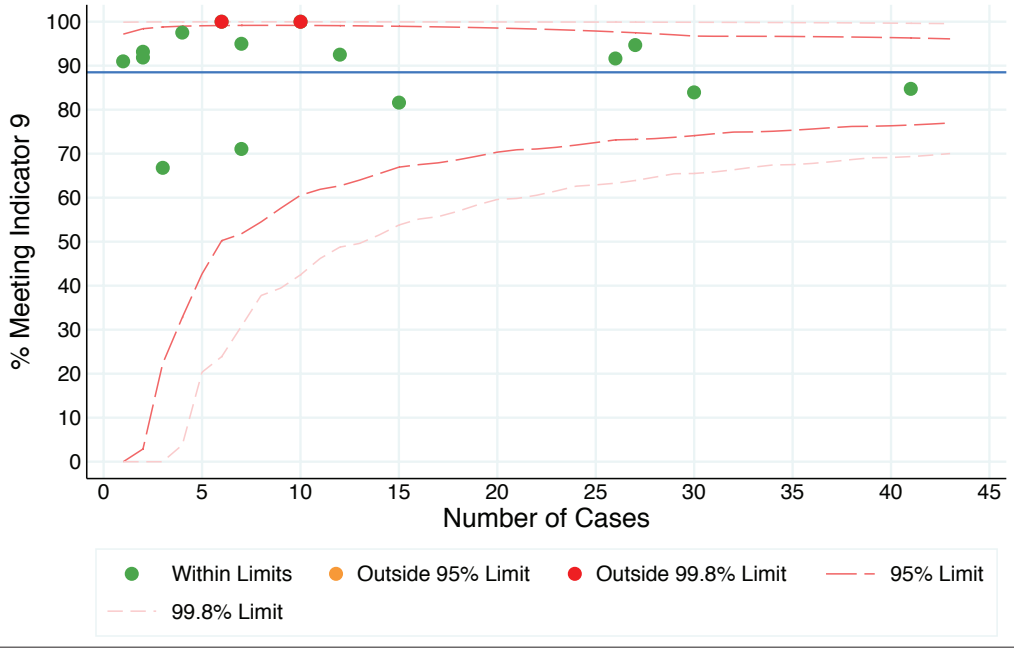


N = 1,643
Notes: Risk adjusted for patient sex, age, birthplace and clinical stage.

TABLE 16: PROPORTION OF PATIENTS WITH NSCLC WHO HAVE UNDERGONE A SURGICAL RESECTION AND CLINICAL STAGE (CTN) AGREES WITH PATHOLOGICAL STAGE (PTN) (QUALITY INDICATOR 9)					
Institution group	Numerator	Denominator	Meeting indicator (crude)	Meeting indicator (risk-adjusted)	Data completeness
1	12	16	75%	79%	62%
2	6	6	100%	97%	12%
3	25	30	83%	81%	94%
4	26	28	93%	91%	93%
5	5	7	71%	69%	14%
6	7	7	100%	92%	37%
7	11	12	92%	89%	57%
8	2	2	100%	89%	20%
9	2	5	40%	64%	100%
10	24	28	86%	88%	68%
11	1	1	100%	88%	20%
12	9	10	90%	99%	34%
13	4	5	80%	94%	38%
14	2	2	100%	90%	67%
15	35	41	85%	82%	72%
Total	**171**	**200**	**86%**		**51%**

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

FIGURE 23: PROPORTION OF PATIENTS WITH NSCLC WHO HAVE UNDERGONE A SURGICAL RESECTION AND CLINICAL STAGE (cTN) AGREES WITH PATHOLOGICAL STAGE (pTN) (QUALITY INDICATOR 9)

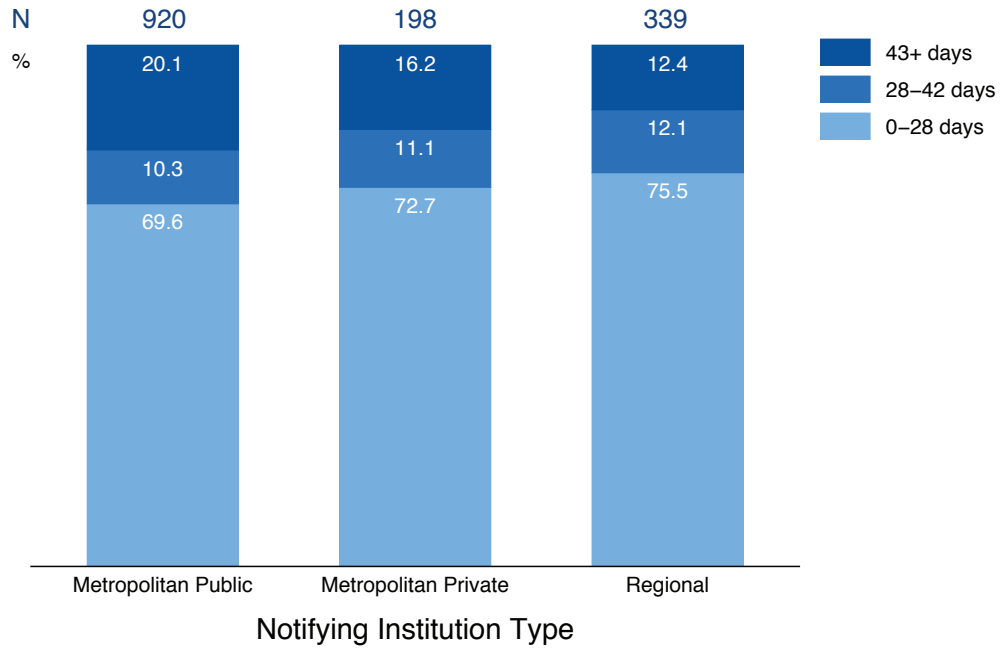


N = 200
Notes: Risk adjusted for patient sex, age, birthplace and clinical stage. The use of this funnel plot to identify potential outliers must be made with caution due to small numbers.

EQUITABLE HEALTH CARE

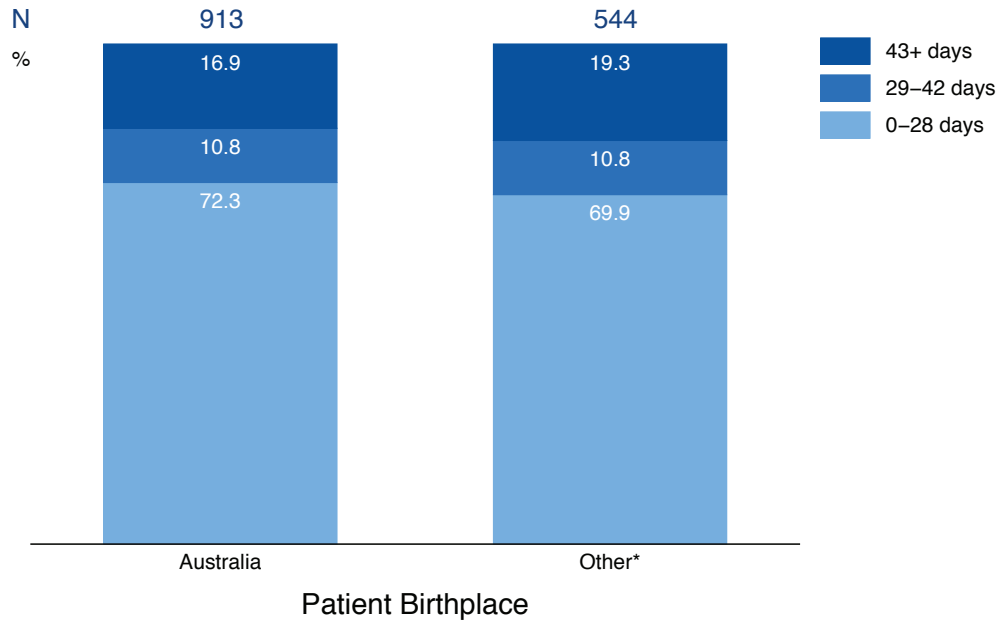
Equitable healthcare may be defined as, **'Equal distribution of healthcare and its benefits, regardless of gender, ethnicity, geographic location or socio-economic status'** [10].

FIGURE 24: REFERRAL TO DIAGNOSIS INTERVAL BY HEALTH SERVICE



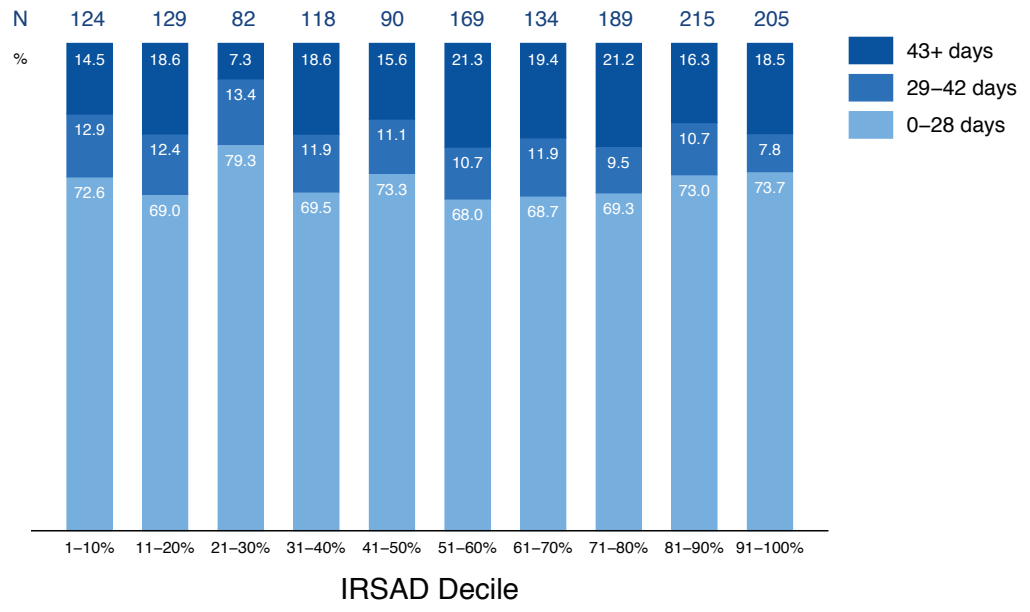
Notes: Pearson's chi-squared test: p-value = 0.03

FIGURE 25: REFERRAL TO DIAGNOSIS INTERVAL BY BIRTHPLACE



Notes: Pearson's chi-squared test: p-value = 0.49.
*Other includes 16 patients with unknown country of birth

FIGURE 26: REFERRAL TO DIAGNOSIS INTERVAL BY SOCIO-ECONOMIC STATUS



Notes: Pearson's chi-squared test: p-value = 0.71
IRSAD 1-10% denotes most socio-economically disadvantaged / least advantaged
IRSAD 91-10% denotes most socio-economically advantaged / least disadvantaged

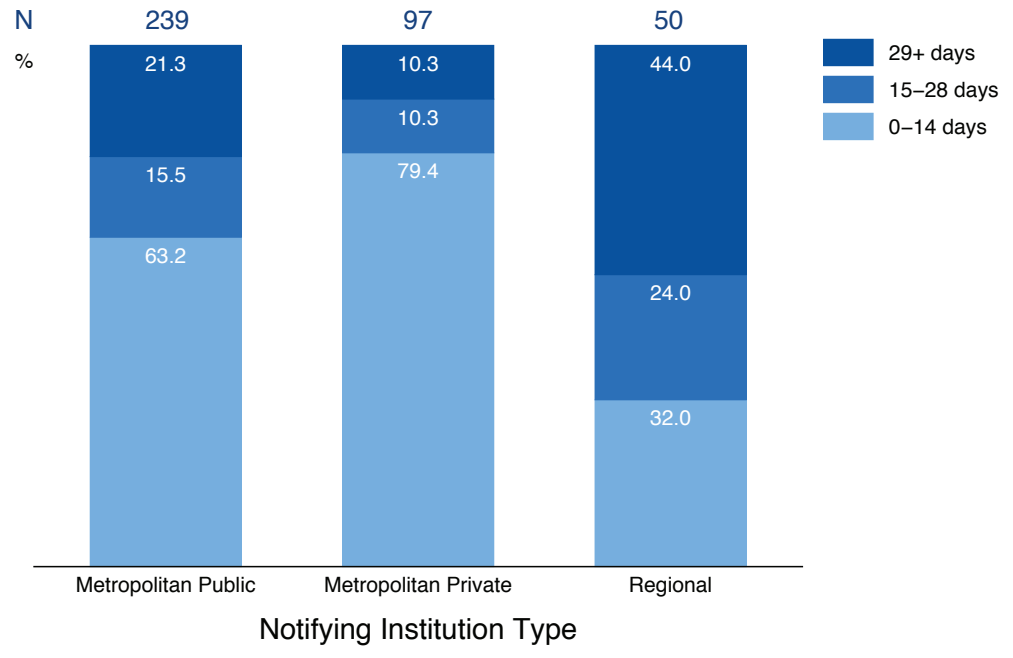
There was a statistically significant difference in timeliness for the referral to diagnosis interval for patients in 2017 when evaluated by the location of the notifying institution (p = 0.03, Figure 24). There was not a statistically significant difference in referral to diagnosis by patient ethnicity (p = 0.49, Figure 25) or socio-economic status (p = 0.71, Figure 26).

Metropolitan public hospitals had a lower proportion of patients achieving rapid diagnosis (within 28 days from referral) and a higher proportion of patients with delayed diagnosis (more than 28 days following referral) compared to Metropolitan Private and Regional hospitals, Figure 24.

Slightly more Australian born patients (72.3%) in 2017 were diagnosed within 28 days from referral compared to non-Australian born patients (69.9%), Figure 25.

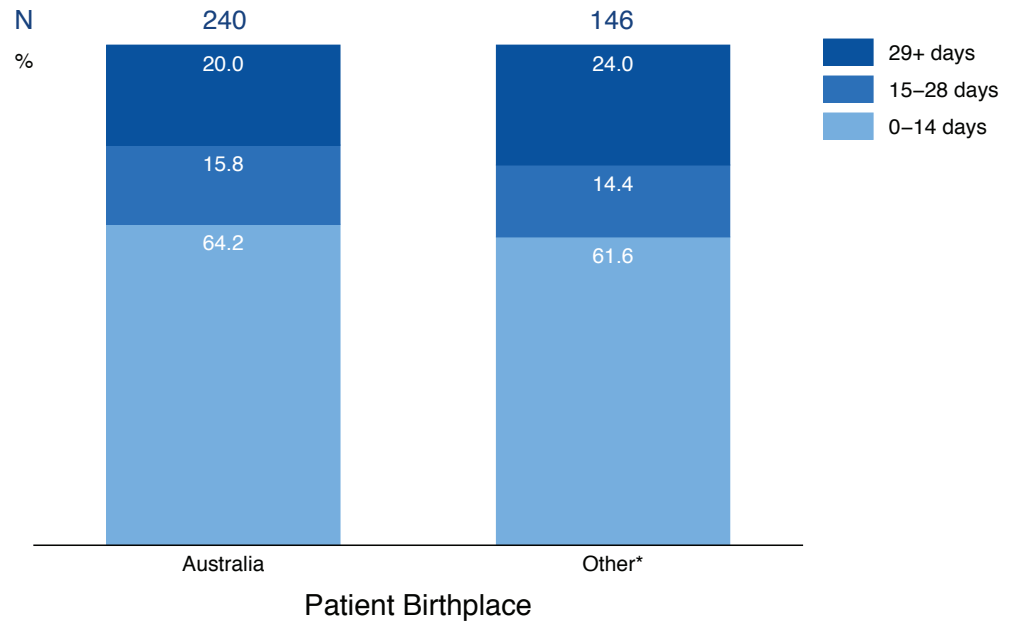
There was not a significant difference in the time interval from referral to diagnosis by socio-economic status, Figure 26.

FIGURE 27: DIAGNOSIS TO RESECTION INTERVAL BY HEALTH SERVICE



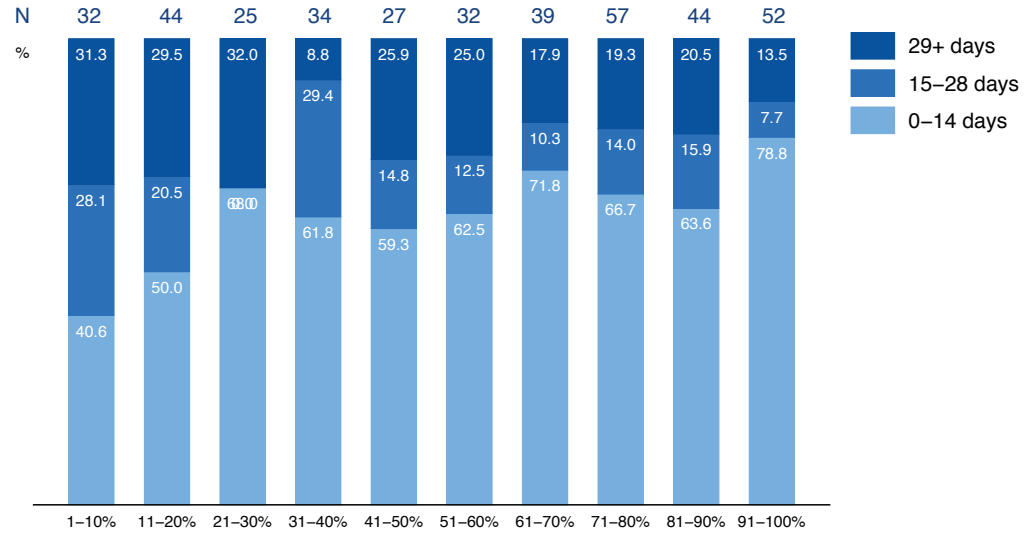
Notes: Pearson's chi-squared test: p-value = 0.71

FIGURE 28: DIAGNOSIS TO SURGICAL RESECTION INTERVAL BY BIRTHPLACE



Notes: Pearson's chi-squared test: p-value = 0.64
*Other includes 16 patients with unknown country of birth

FIGURE 29: DIAGNOSIS TO SURGICAL RESECTION INTERVAL BY SOCIO-ECONOMIC STATUS



Notes: Pearson's chi-squared test: p-value = 0.03
IRSAD 1-10% denotes most socio-economically disadvantaged / least advantaged
IRSAD 91-10% denotes most socio-economically advantaged / least disadvantaged
Two patients with unknown IRSAD were excluded

A higher proportion of patients from private institutions were resected within 14 days of referral (79.4%), compared with patients from metropolitan public or regional institutions (63.2%, 32% respectively), although the results were not statistically significant (p = 0.71), Figure 27.

The timeliness of surgical resection for patients in 2017 by patient ethnicity was not significantly different (Australia 64.2%, Other 61.6%, p = 0.64).

The time interval by socio-economic status indicates patients in the higher decile (most advantaged) had more resections within 0-14 days of referral (78.8%) compared with the lowest decile (40.6%) p = 0.03, Figure 29.

The VLCR is a CQR that aims to assist health services to identify targets for improvement, by collecting data across multiple health services, and reporting key process and outcome measures of the patient pathway.

APPENDICES

APPENDIX A: LIST OF FIGURES		
Page	Figure Number	Figure Title
6	Figure 1	VLCR Data collection process
7	Figure 2	Cumulative VLCR patient registrations 2011–2016
8	Figure 3	VLCR Survival analysis: 2011–2016 Cohort
10	Figure 4	VLCR Survival analysis by sex: 2011–2016 Cohort
10	Figure 5	VLCR Survival analysis by age group: 2011–2016 Cohort
11	Figure 6	VLCR Survival analysis by clinical stage: 2011–2016 Cohort
13	Figure 7	Sex
13	Figure 8	Smoking status
15	Figure 9	Patient age profile by sex
18	Figure 10	Lung cancer type
18	Figure 11	NSCLC type
19	Figure 12	Clinical staging for NSCLC patients
21	Figure 13	Funnel plot example
22	Figure 14	Proportion of patients with NSCLC who have had a resection and date of death within 30 days of surgery (QI 18)
23	Figure 15	Proportion of patients undergoing resection with documented PET scan (QI 10)
24	Figure 16	Proportion of patients with NSCLC (clinical stage IIIB and IV) who have ECOG (0-1) who have commenced chemotherapy (QI 20)
25	Figure 17	Proportion of patients with NSCLC (clinical stage I or II) who have had a surgical resection (QI 14)
26	Figure 18	Proportion of patients with screening for supportive care documented (QI 5)
27	Figure 19	Proportion of patients with NSCLC (stage IV) referred to any palliative care services within 8 weeks of diagnosis (QI 23)
28	Figure 20	Proportion of patients where referral to diagnosis date is within 28 days (QI 1)
29	Figure 21	Proportion of patients with NSCLC where time from diagnosis to surgical resection is within 14 days (QI 3)
30	Figure 22	Proportion of patients with presentation at a lung cancer multidisciplinary meeting (MDM) documented (QI 11)
31	Figure 23	Proportion of patients with NSCLC who have undergone a surgical resection and clinical stage (cTN) agrees with pathological stage (pTN) (QI 9).
32	Figure 24	Referral to diagnosis interval by health service
32	Figure 25	Referral to diagnosis interval by birthplace
33	Figure 26	Referral to diagnosis interval by socio-economic status
34	Figure 27	Diagnosis to surgical resection interval by health service
34	Figure 28	Diagnosis to surgical resection interval by birthplace
35	Figure 29	Diagnosis to surgical resection interval by socio-economic status

APPENDIX B: LIST OF TABLES AND GLOSSARY

Page	Table Number	Figure Title
7	Table 1	VLCR Patient registrations by year
9	Table 2	VLCR Crude survival rates at time intervals after diagnosis
14	Table 3	Language, birthplace and indigenous status
15	Table 4	Patient age grouping by sex
16	Table 5	Patient socio-economic profile
19	Table 6	Patient ECOG status at diagnosis
22	Table 7	Proportion of patients with NSCLC who have had a resection and date of death within 30 days of surgery (QI 18)
23	Table 8	Proportion of patients undergoing resection with documented PET scan (QI 10)
24	Table 9	Proportion of patients with NSCLC (clinical stage IIIB and IV) who have ECOG (0-1) who have commenced chemotherapy (QI 20)
25	Table 10	Proportion of patients with NSCLC (clinical stage I or II) who have had a surgical resection (QI 14)
26	Table 11	Proportion of patients with screening for supportive care documented (QI 5)
27	Table 12	Proportion of patients with NSCLC (stage IV) referred to any palliative care services within 8 weeks of diagnosis (QI 23)
28	Table 13	Proportion of patients where referral to diagnosis date is within 28 days (QI 1)
29	Table 14	Proportion of patients with NSCLC where time from diagnosis to surgical resection is within 14 days (QI 3)
30	Table 15	Proportion of patients with presentation at a lung cancer multidisciplinary meeting (MDM) documented (QI 11)
31	Table 16	Proportion of patients with NSCLC who have undergone a surgical resection and clinical stage (cTN) agrees with pathological stage (pTN) (QI 9).

GLOSSARY

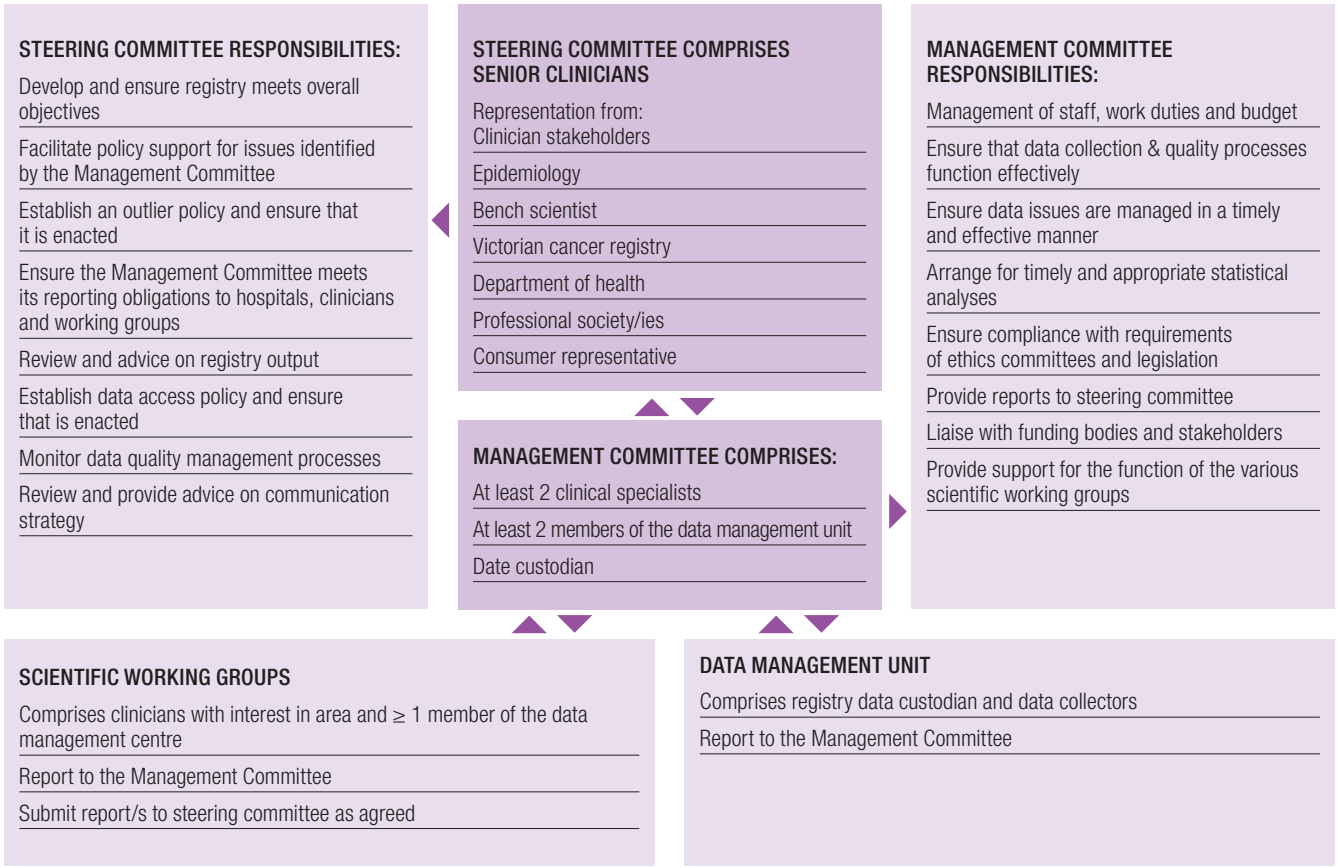
CCV	Cancer Council Victoria	PET	Positron emission tomography scan
CT	Computed tomography scan	pTN	Pathological stage of primary tumour
cTNM	Clinical stage of primary tumour	SCLC	Small cell lung cancer
ECOG	Eastern Cooperative Oncology Group Performance status score	VATS	Video-assisted thoracoscopic surgery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

APPENDIX C: 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 D: 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 Zalcberg	Tony Charlton Chair of Oncology, Alfred Health. Head, Cancer Research Program, School of Public Health and Preventive Medicine, Monash University.

APPENDIX E: CLINICAL QUALITY INDICATORS		
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
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 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.

APPENDIX F: 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.

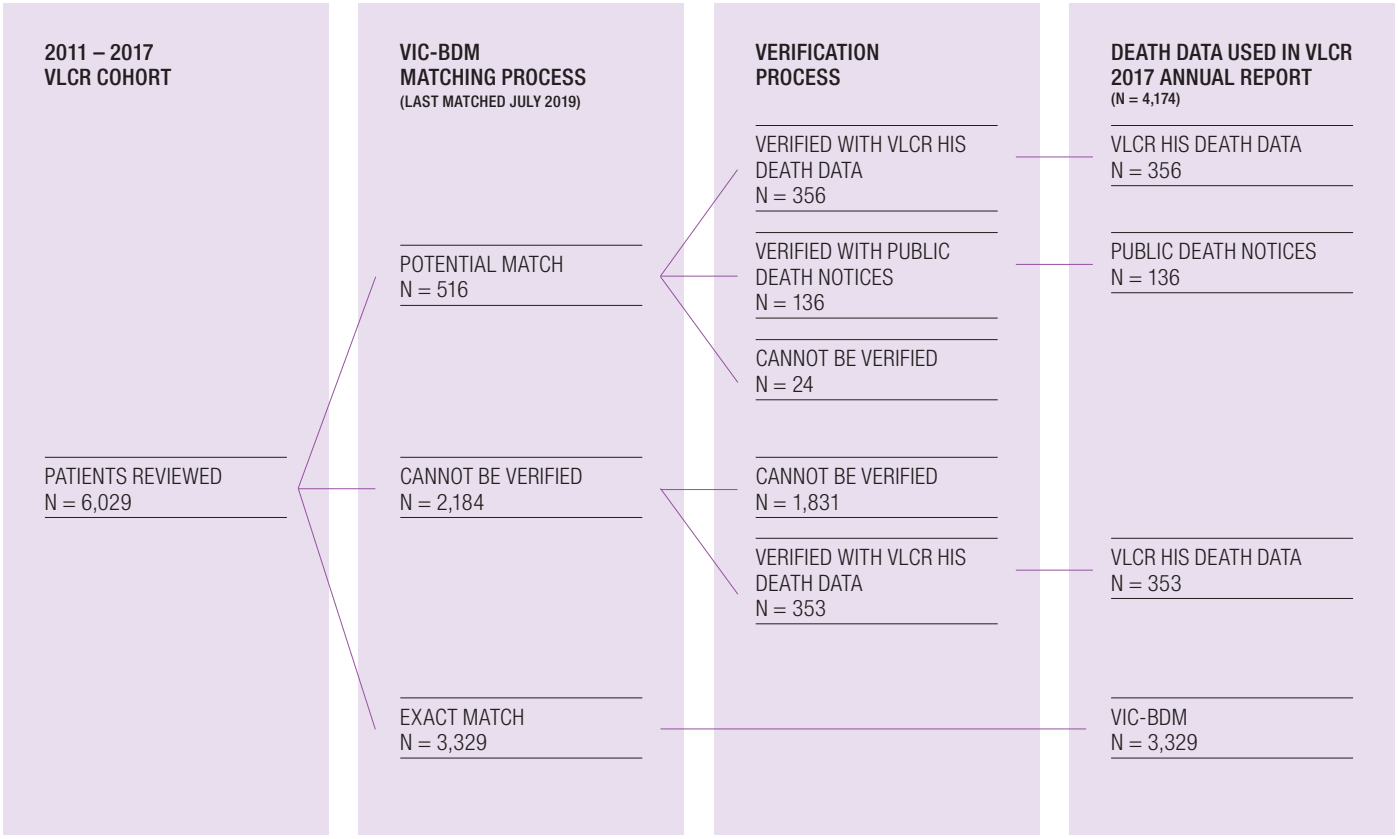
Case ascertainment for VLCR will occur via notification by participating site Health Information Systems of hospital discharges confirming ICD 10 coding identifying lung cancer as the principal reason for admission. Prevalence cases are discarded and incident cases are reviewed for inclusion and exclusion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

1. Jakobsen E1, Green A, Oesterlind K, Rasmussen TR, Iachina M and Palshof T. Nationwide quality improvement in lung cancer care: the role of the Danish Lung Cancer Group and Registry. Journal of Thoracic Oncology 2013 October; 8(10):1238-47.
2. Victorian Cancer Agency. The Victorian Lung Cancer Registry (VLCR) pilot study 2010. Victorian Lung Cancer Registry School of Public Health & Preventive Medicine Monash University and Alfred Centre. http://vlcr.registry.org.au/home
3. Australian Government Cancer Australia. Request for submissions: Lung cancer service delivery. Collaborations to demonstrate best practice approaches to lung cancer treatment and care. Cancer Australia, Strawberry Hills, NSW 2012.
4. Department of Health Victoria. Redesigning Hospital Care Program Tools. Health Improvement Capability Quotient guide: Define, measure and create capability for improvement. http://www.health.vic.gov.au/redesigningcare/tools.htm
5. Department of Health Victoria. Redesigning Hospital Care Program: An introduction to process redesign.
6. Weller D, Vedsted P, Rubin G,Walter FM, Emery J, Scott S, Campbell C, Andersen RS, Hamilton W, Olesen F, Rose P, Nafees S, Rijswijk E, Hiom S, Muth C, Beyer M and Neal RD. Guideline The Aarhus statement: improving design and reporting of studies on early cancer diagnosis. British Journal of Cancer (2012) 106, 1262 – 1267 & 2012 Cancer Research UK All rights reserved 0007 – 0920/12.
7. AIHW, Cancer in Australia 2019. CAN 123. 2019, Australian Institute of Health and Welfare: Canberra.
8. Cancer Council Australia, Australian Government, Lung Cancer Statistics, updated 2018.
9. Cancer Council Victoria, “Lung Cancer revealed as biggest killer in Victorian women”, January 2018.
10. Australian Commission on Safety and Quality in Health Care, Framework for Australian clinical quality registries. Sydney. ACSQHC, March 2014.
11. Sampurno F EA, Kumari V, Millar J, Davis ID, Giles GG, Murphy D, Frydenberg M, Kearns P, Evans SM. Quality of care achievements of the Prostate Cancer Outcomes Registry-Victoria. Med J Aust 2016.
12. Clinical Quality Registries Outlier Management Policy, Registry Sciences Unit, Monash University, 2017.
13. Australian Bureau of Statistics, 2018. 2033.0.55.001 - Census of Population and Housing: Socio-Economic Indexes for Area (SEIFA), Australia, 2016. http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/2033.0.55.0012016?Open Document (Accessed: 3 May 2018).
14. Institute of Medicine Report “Crossing the quality chasm-A new health system for the 21 st century” (2001) Institute of Medicine (US) Committee on Quality of Health Care in America. Washington (DC): National Academies Press (US); 2001.

APPENDIX I: 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, Abrahm 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.

MONASH University

Victoria Lung Cancer Registry
Monash University
Level 3,
553 St Kilda Rd,
Melbourne Victoria 3004