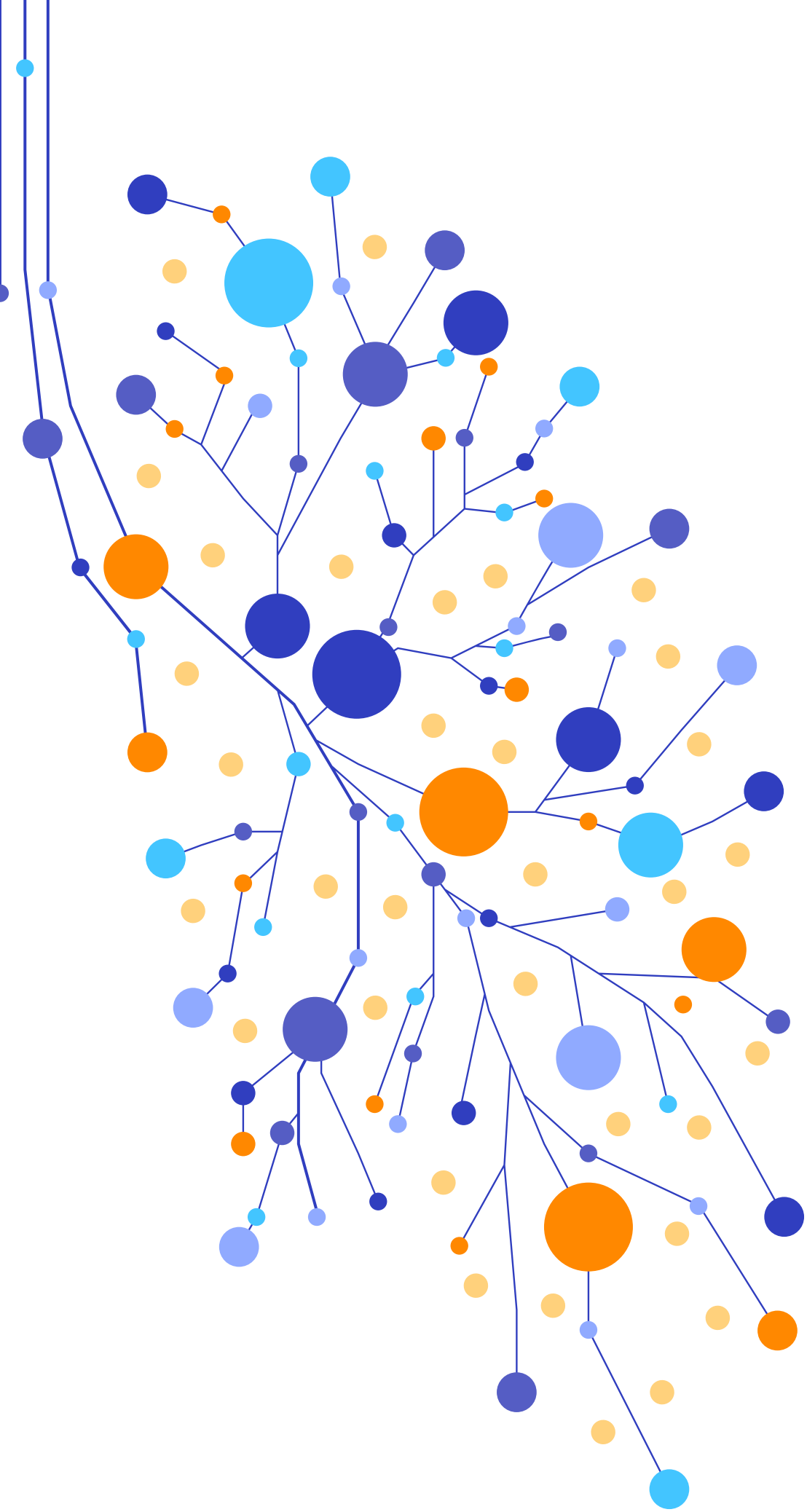


Victorian Lung Cancer Registry

Annual Report 2019

VLCR

MONASH University

Contents

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

Stirling R, Martin C, Brand M, Smith S, McNeil J, Zalcberg J on behalf of the Victorian Lung Cancer Registry. The Victorian Lung Cancer Registry Annual Report, 2019. Monash University, Department of Epidemiology and Preventive Medicine, Report No 5, pages 47.

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

Victorian Lung Cancer Registry Monash University
Level 2 553 St Kilda Rd Melbourne VIC 3004
Phone: +61 3 9903 0206
Fax: +61 3 9903 0556
Email: med-cancerregistries@monash.edu

Foreword

It is with great pleasure that I present the Victorian Lung Cancer Registry (VLCR) 2019 Annual Report. This represents the first report of the COVID-19 era and highlights the critical importance of the availability of high-quality contemporaneous data to support healthcare planning during such system shocks. The pandemic has created significant challenges for all during this year and we are extremely grateful for the ongoing support and contribution of all of our stakeholders during this difficult time.

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 and decision making 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 2019 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 2019 calendar year.

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 to the VLCR Project Manager Margaret Brand, VLCR Research Officer Shantelle Smith 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, FISQua, MRCPI, FRACP

Coordinating Principal Investigator, Steering Committee Chairman
Victorian Lung Cancer Registry

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 cost effective in reducing heath care spending [6]. The VLCR data report 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 2019 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 2019:

Patients:

New registrations were 43.7% females and 56.3% males, with a mean age of diagnosis of 69.3 years for females and 70.4 years for males. Current smokers represent 38.8% for new registrations and never smokers 11.5%. Patients born outside Australia represent 37% and those identifying with Aboriginal and Torres Straits Island status were 0.9%.

Non-Small Cell Lung Cancer (NSCLC) was the most frequent histology identified at 85.5%, of which Adenocarcinoma comprised 62.5%, Squamous Cell 20.8% and Not otherwise Specified 16.2%.

Management:

Over 2/3 (69%) of patients were presented to the Multi-Disciplinary Meeting prior to treatment. Active anti-cancer treatment was delivered to 84% of patients: 27% underwent surgical resection, 50% radiotherapy and 50% received 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 remains high (96%).

Chemotherapy treatment:

Provision of chemotherapy to NSCLC patients with advanced disease (IIIB/IV) and good performance status (ECOG <2), was high (81%), but there is variation between health services (59- 100%).

Supportive care screening:

Evidence of screening patients using the Supportive Care Screening Tool and Distress Thermometer remains low (31%), with significant variation between health services (2-79%). 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 2019, we report that of the 797 patients who presented with stage IV NSCLC, only 41% had documentation indicating they were referred to palliative care within 8 weeks of diagnosis. There was a wide variation across health services (10-80%).

Timeliness of care:

Referral to diagnosis within 28 days was recorded for 69% of patients, with wide variation between health services (58-87%). Time from diagnosis to surgical treatment within 14 days was recorded for 54% of patients with NSCLC.

Timeliness of care by geographical region: Metropolitan Public hospitals had a lower proportion of patients achieving timely diagnosis (within 28 days from referral) when compared to Metropolitan Private and Regional hospitals (66.5 vs 76.3 and 71.5, Chi2 p=.053).

Survival analysis:

Based on 2011-2019 registrations, the median survival time is 1.28 years. . Kaplan-Meier estimates show 55.4% survival at one year and 27.1% survival 5 years from diagnosis. Survival rates at one year are lower for patients diagnosed after 80 years of age (39.7% vs 56.1% for 70-79 years) and also lower for patients presenting at a later clinical stage (stage IV, 34.6% and stage I, 91.1%).

Equity:

The time interval from referral to diagnosis by socio-economic status showed the most advantaged group (91-100%) had the highest proportion of patients with rapid diagnosis (within 28 days of referral), 74.3% and the 21-30% group has the lowest proportion of patients with rapid diagnosis (61.1% Chi2 p=0.02).

A higher proportion of patients from Metropolitan Private hospitals are resected within 14 days of diagnosis compared with patients from Metropolitan public or Regional hospitals (71.6% vs 52.8% vs 45.7% respectively) and a higher proportion of regional patients have delayed time to resection (>14 days) compared to metropolitan public and metropolitan private hospitals (54.2% compared to 47.1% and 28.3% respectively), Chi2 p=0.02. Analysis using IRSAD shows the most advantaged patients (91-100% decile) had a higher proportion of patients resected within 14 days, when compared with the most disadvantaged (1-10% decile), (58.3% vs 2.5%, although this was not statistically significant (Chi2 p=0.26).

Annual Report 2019

REGISTRY OVERVIEW AND REPORTING

Lung Cancer remained the fourth most commonly diagnosed cancer in Victoria in 2019 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].

The VLCR objective and design is concordant with the National Clinical Quality Registry and Virtual Registry Strategy 2020-2030 (the Strategy) which aims to drive continuous improvements in the value and quality of patient-centred health care to achieve better health outcomes for all Australians.

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 report 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. CQR 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 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 VLCR provides two risk-adjusted benchmarked reports. The Quality Indicator (QI) Report includes 20 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 2019 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. The 2019 Annual Report is the sixth publicly available report produced by the VLCR.

DATA COLLECTION

In 2019, 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 2,114 eligible and consented new registry patients for 2019, 57 patients (2.6%) declined consent and were excluded from the registry. The total number of patients registered from 2011-2019 is 10,552.

The data contained in this document were extracted from the VLCR in March 2021 for patients diagnosed with primary lung cancer from 1st January to 31st December, 2019. 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 2019 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 March 13th, 2021 (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 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, 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.

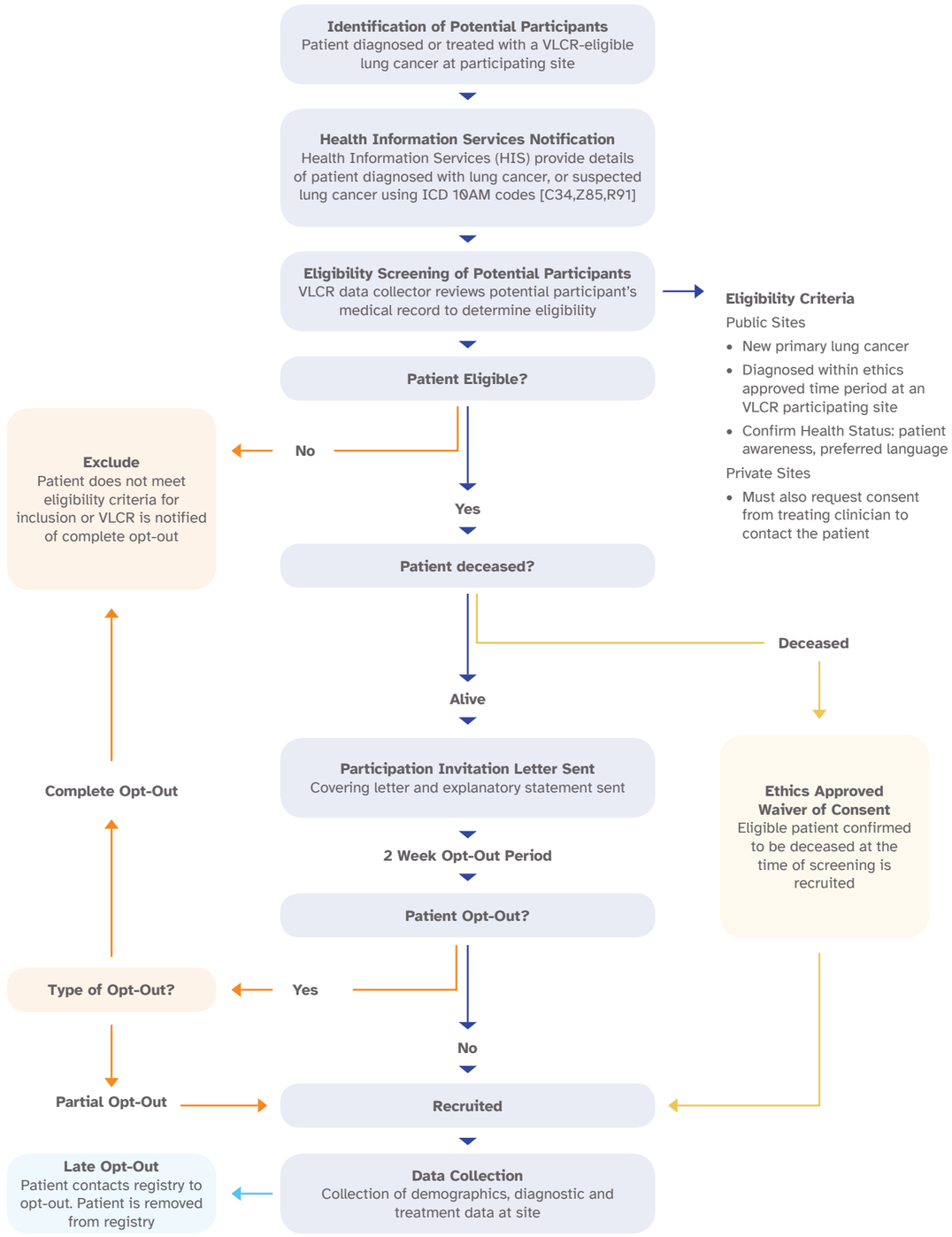
Stage 1: Patients diagnosed with a principal diagnosis of lung cancer are currently identified through coded admissions data at participating sites. The medical record is then reviewed to identify the health status and the date of diagnosis of the patient, to enable an explanatory statement to be sent 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: Patient reported outcomes are being collected for selected sites participating in a sub-study and results will be included in future reports. The Registry aims to collect patient reported outcomes for all sites.

VLCR Workflow

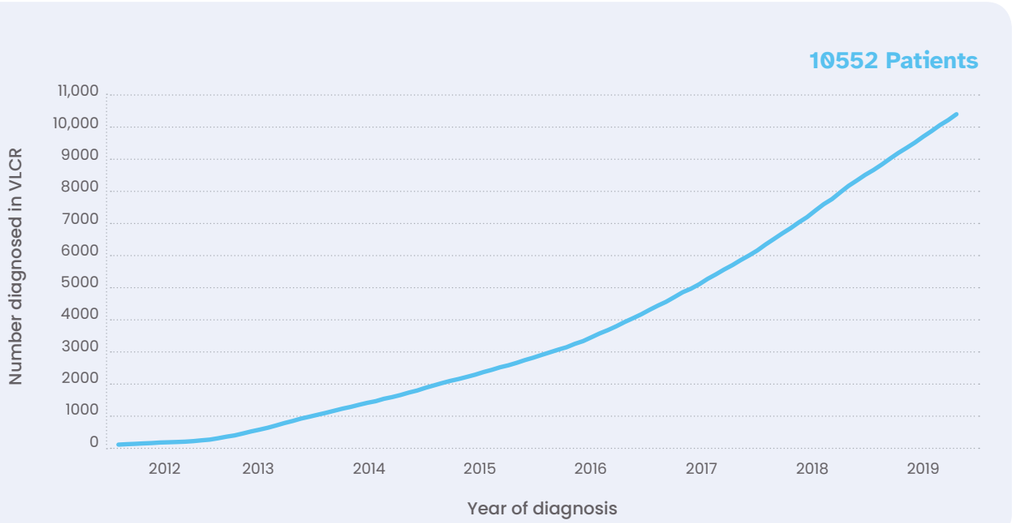
Figure 1 *Participant recruitment and data transfer in the VLCR*



Registry Site Participation

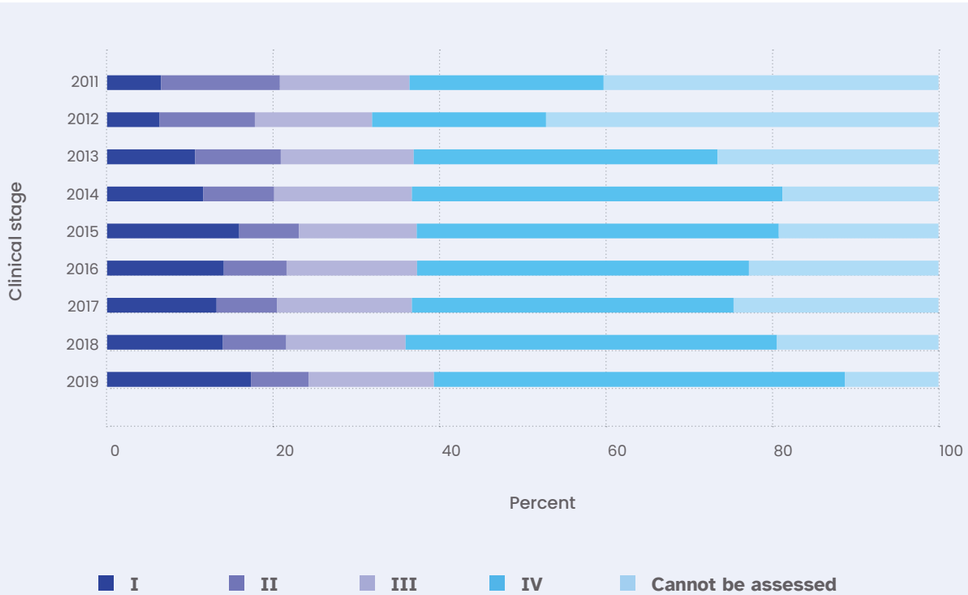
REGISTRY SITE PARTICIPATION

Figure 2 *below shows the total number of participant registrations by year, from 2011 to December 2019 (N = 10,552). In 2019, 2,114 new lung cancer cases were captured by the VLCR.*



Note: 10552 VLCR patient registrations as at December 2019

Figure 3 *below lists the cumulative patient registrations from 2011–2019 by clinical stage.*



Survival Analysis 2011-2019 Registrations

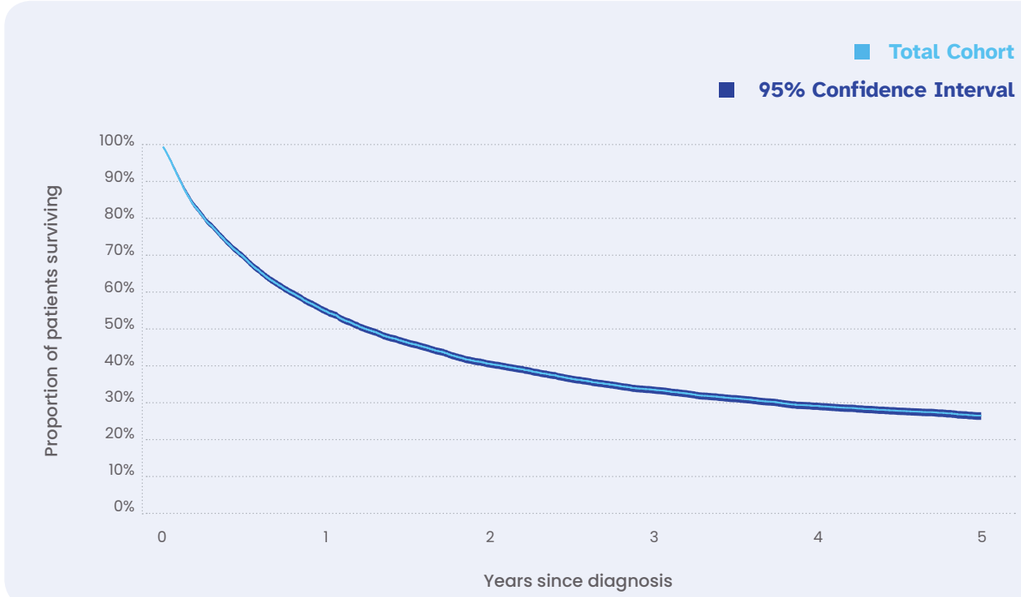
Kaplan-Meier estimates of survival using 2011-2019 VLCR registrations are presented in Figure 4 and Table 1 (n=10,552). Survival is also stratified by sex, age quartile groups and clinical stage in Figures 4-6. Survival rates are presented at annual time intervals from date of diagnosis with no adjustment 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 March 13th, 2021. 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.

Figure 4 *VLCR total cohort survival*



Number at risk	0	1	2	3	4	5
	10,552	5,841	3,617	2,211	1,337	793

Based on 2011-2019 VLCR patient registrations, the median survival time is 1.28 years [CI 1.218-1.336] The Kaplan-Meier estimates show 55.4% [CI 54.4-56.3] survival at one year after diagnosis and 27.1% [CI 26.1-28.2] at five years after diagnosis, Figure 4 and Table 1.

Table 1 *VLCR 2011-2019 Crude Survival Rates at Time Intervals After Diagnosis*

	Diagnosed	Deceased (%)	Crude survival at time after diagnosis (95% Confidence Interval)		
			1 Year	2 Years	5 Years
All	10552	7107 (67.4%)	55.4 (54.4 - 56.3)	41.1 (40.2 - 42.1)	27.1 (26.1 - 28.2)
Sex					
Female	4563	2864 (62.8%)	59.7 (58.2 - 61.1)	46.0 (44.5 - 47.4)	31.5 (29.9 - 33.1)
Male	5989	4243 (70.8%)	52.1 (50.8 - 53.3)	37.5 (36.2 - 38.7)	23.8 (22.5 - 25.1)
Age					
<60	1814	1104 (61.1%)	63.1 (60.9 - 65.3)	47.6 (45.3 - 49.9)	33.9 (31.3 - 36.4)
60-70	3098	1978 (63.8%)	60.0 (58.3 - 61.7)	44.9 (43.1 - 46.6)	30.2 (28.2 - 32.1)
70-79	3643	2411 (66.2%)	56.1 (54.5 - 57.7)	42.2 (40.6 - 43.8)	28.5 (26.7 - 30.3)
≥80	1997	1614 (80.1%)	39.7 (37.6 - 41.8)	27.5 (25.6 - 29.5)	13.8 (11.9 - 15.8)
Clinical stage*					
I	1431	416 (29.1%)	91.1 (89.5 - 92.5)	81.4 (79.2 - 83.3)	63.9 (60.6 - 67.1)
II	827	410 (49.6%)	80.2 (77.3 - 82.7)	64.3 (60.9 - 67.5)	45.4 (41.3 - 49.4)
III	1612	1035 (64.2%)	65.4 (63.1 - 67.7)	46.6 (44.0 - 49.0)	27.6 (24.9 - 30.3)
IV	4452	3800 (85.4%)	34.6 (33.2 - 36.0)	19.6 (18.4 - 20.8)	9.8 (8.7 - 11.0)
Unknown	2230	1446 (64.8%)	57.4 (55.3 - 59.4)	45.6 (43.5 - 47.7)	30.6 (28.3 - 32.8)

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

Figure 5 *VLCR survival analysis by sex 2011-2019*

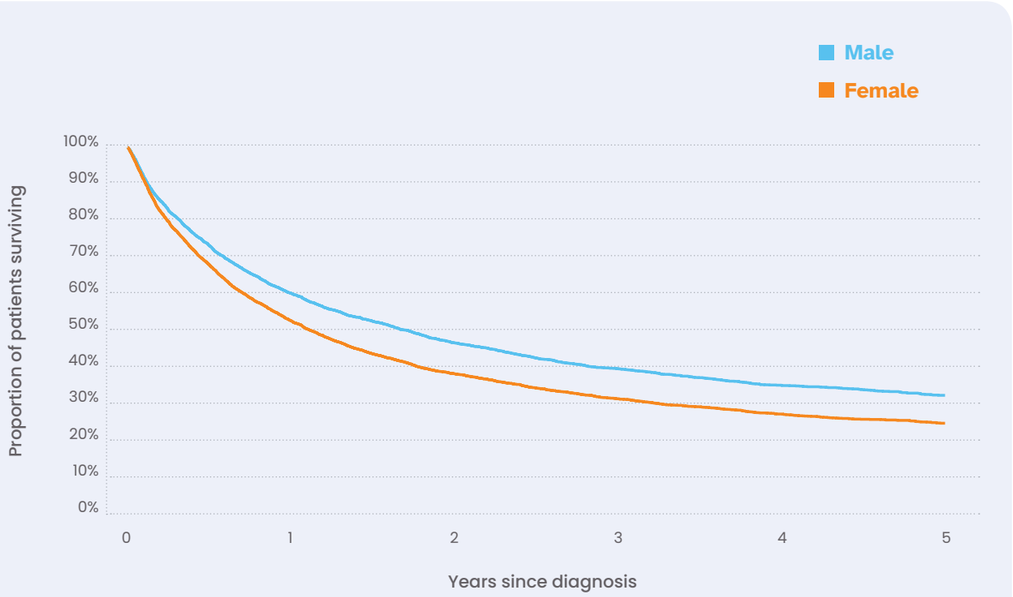
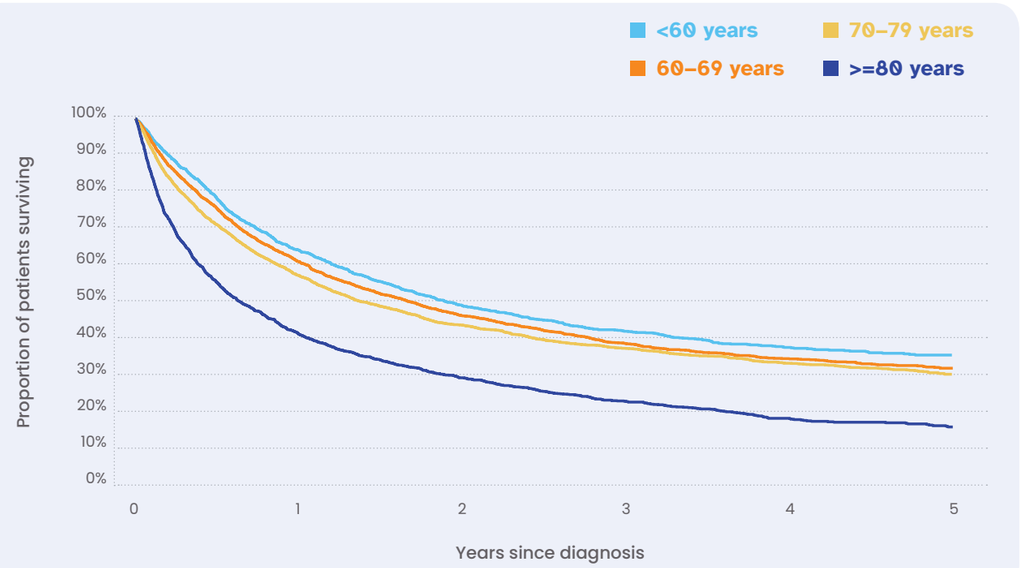


Figure 6 *VLCR survival analysis by age group 2011-2019*

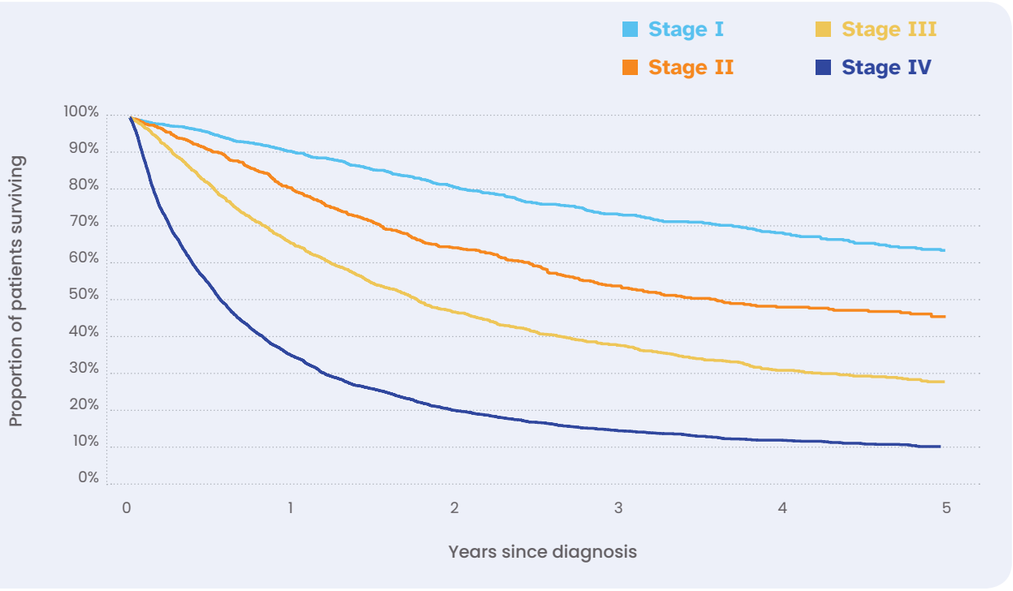


Number at risk	0	1	2	3	4	5
<60 years	1,814	1,145	723	468	293	182
60-69 years	3,098	1,859	1,150	681	430	269
70-79 years	3,643	2,044	1,285	801	475	266
>=80 years	1,997	793	459	261	139	76

Female survival was higher at one year after diagnosis than male survival (Female: 59.7% [CI 58.2-61.1]; Male: 52.1% [CI 50.8-53.3]) and also at five years after diagnosis (Female: 31.5% [CI 29.9-33.1], Male: 23.8% [CI 22.5-25.1]), Table 1 and Figure 5.

Survival rates are lower for patients diagnosed after 80 years of age; survival at one year for the 80 years and over cohort is just 39.7%, whereas survival at one year for those diagnosed before 60 years of age is 63.1%, Table 1 and Figure 6.

Figure 7 *VLCR survival analysis by stage 2011-2019*



Number at risk	0	1	2	3	4	5
Stage I	1,431	1,327	950	618	400	229
Stage II	827	663	458	285	186	120
Stage III	1,612	1,055	617	381	208	128
Stage IV	4,452	1,540	696	352	196	104

Figure 7 Crude survival rates are lower for patients presenting at a later clinical stage; survival at one year for Stage I patients is 91.1% and only 34.6% for Stage IV patients,

Table 1 and Figure 7 Note. Clinical stage unknown, n=2,230 (21%).

> For many years I would see and hear about significant variations in care within the lung cancer community. Thankfully, this gap is continuing to close and significant improvements in quality of care have been achieved. As a person living with lung cancer, being involved in the Victorian Lung Cancer Registry helps to provide meaning and purpose behind the work that is conducted by all stakeholders involved, and a unique opportunity for our united voice to help drive change.

Lisa Briggs
Lung Cancer Patient Advocate
VLCR Consumer Representative

VLCR Patient Characteristics 2019

Age, sex, smoking status, indigenous status, country of birth, preferred language and socio-economic profile.

In the 2019 period there were a greater number of male than female participants, Figure 8 (56.3% vs 43.7%).

In 2019, approximately half (49.7%) of participants with available smoking status identified as an ex-smoker, 38.8% were current smokers and 11.5% had never smoked, Figure 9.

Figure 8 *VLCR 2019 Sex*

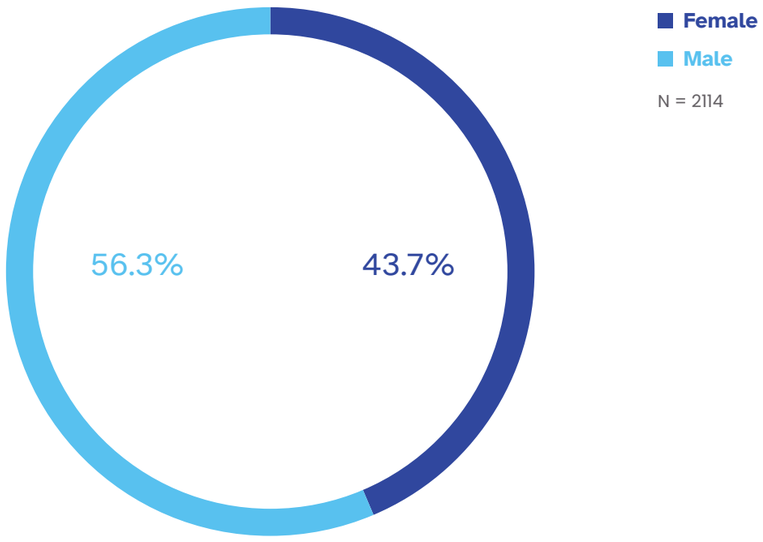


Figure 9 *VLCR 2019 Smoking status*

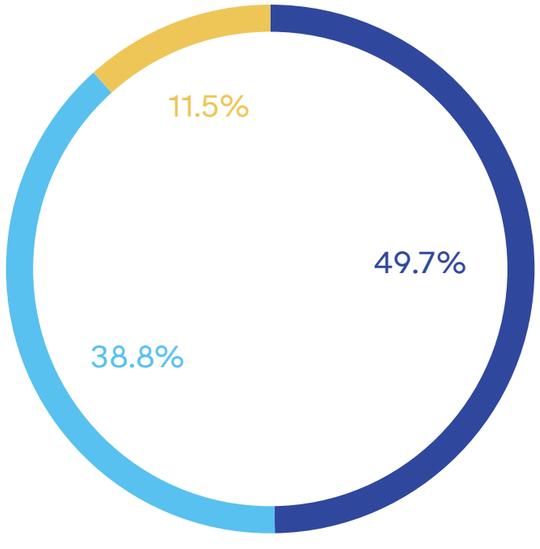


Table 2 *VLCR 2019 Language, Birthplace and Indigenous Status*

	Number	Percent
Country of Birth		
Australia	1326	62.7%
England	20	0.9%
Italy	71	3.4%
Greece	70	3.3%
Scotland	29	1.4%
Poland	20	0.9%
Germany	24	1.1%
Malta	30	1.4%
Netherlands	32	1.5%
China	50	2.4%
Other	442	20.9%
Total	2114	100%
Preferred Language		
English	1922	90.9%
Greek	43	2%
Italian	14	0.7%
Mandarin	26	1.2%
Vietnamese	30	1.4%
Cantonese	13	0.6%
Russian	2	0.1%
Turkish	13	0.6%
Croatian	3	0.1%
Macedonian	7	0.3%
Other	41	1.9%
Total	2114	100%
Aboriginal Torres Strait Islander (ATSI) status		
ATSI	20	0.9%
Non ATSI	2063	97.6%
Unknown	31	1.5%
Total	2114	100%

In 2019 the majority of VLCR participants were born in Australia, 62.7% Table 2.

English was identified as the first language by 90.9% of participants and 0.9% of participants identified themselves as Indigenous Australians, Table 2.

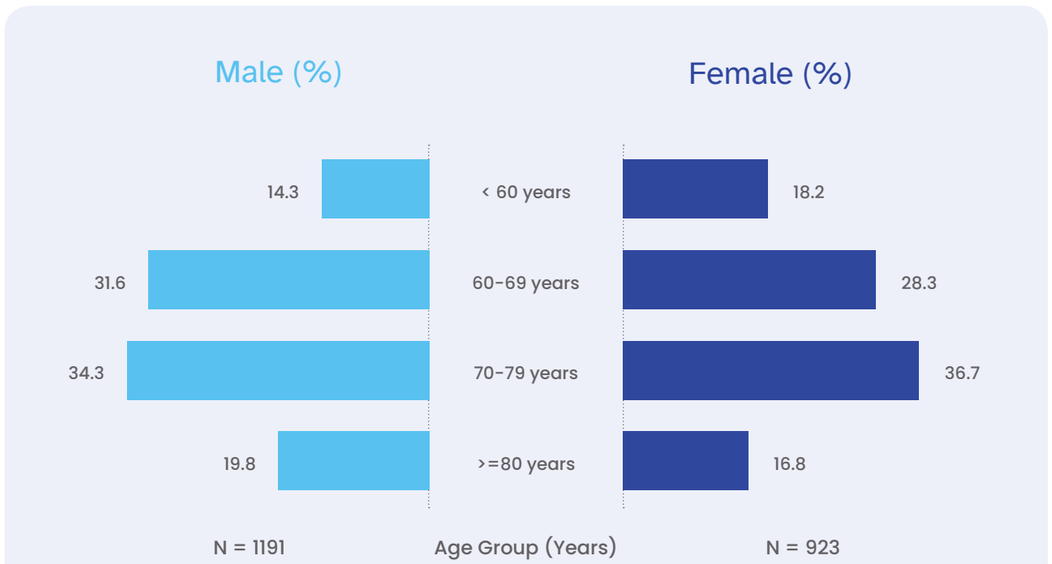
ATSI identification is provided by participating site administrative data. Therefore, if ATSI patients are not admitted to a participating institution, or do not identify their ATSI status on admission, they will not be represented in these figures, Table 2.

Table 3 *VLCR 2019 Patient Age Profile By Sex*

	Male	Female	p-value (test)
Age	N = 1,191 (56.3%)	N = 923 (43.7%)	
Mean (Standard Deviation)	70.4 (10.4)	69.3 (10.8)	0.018

Male participants were on average, 1.1 years older than females at diagnosis, Table 3 (69.3 vs 70.4; p=0.018).

Figure 10 *VLCR 2019 Patient Age Profile by Sex*



The highest incidence at diagnosis is in the 70-79-year age groups for both males and females (overall 35.3% total new cases in 2019), with those diagnosed prior to 60 years of age representing 16% of new cases in 2019, 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: *2019 Patient Socio-Economic Profile*

2019 PATIENT SOCIO-ECONOMIC PROFILE		
SEIFA – IRSAD Decile	Number	Percent
1-10% (most disadvantaged)	196	9.27%
11-20%	200	9.46%
21-30%	153	7.24%
31-40%	202	9.56%
41-50%	135	6.39%
51-60%	311	14.71%
61-70%	200	9.46%
71-80%	221	10.45%
81-90%	306	14.47%
91-100% (most advantaged)	189	8.94%
Unknown	1	0.05%
Total	**2114**	**100%**

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 2019.

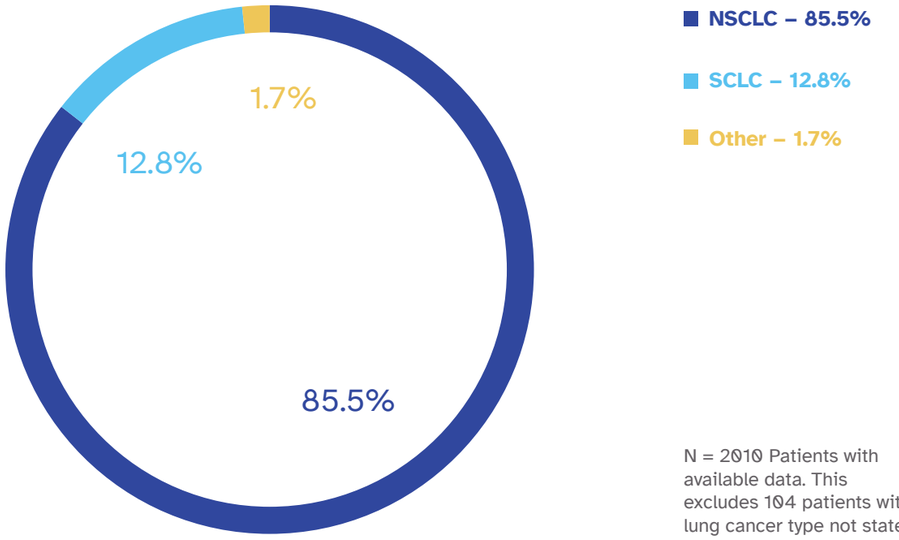
Of the 2019 VLCR patient cohort, the patient socio-economic profile appears dispersed, 23.42% lived in postal areas at diagnosis that were ranked in the top 20% (most advantaged areas). On the other socio-economic spectrum, 18.73% of the 2019 VLCR patients lived in areas ranked in the lowest 20% (most disadvantaged areas).

VLCR Lung Cancer Types 2019

Cancer cell type is presented in Figure 11. Non-Small Cell Lung Cancer (NSCLC) was the most frequent histology identified at 85.5%, Small Cell Lung Cancer (SCLC) comprised 12.8%, and 1.7% presented with other lung cancer types. Lung cancer type was not identifiable for 104 patients (4.9%) diagnosed in 2019, which includes patients 88 patients (4.1%) without a pathological diagnosis.

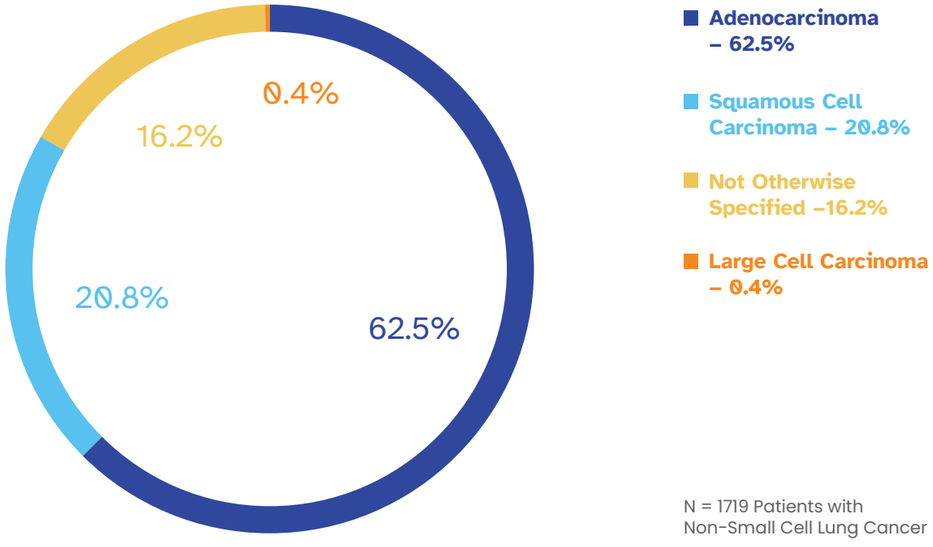
Of the 1,719 diagnosed with NSCLC in 2019, 62.5% had Adenocarcinoma, 20.8% had Squamous Cell Carcinoma, 0.4% had Large Cell Carcinoma and the remaining 16.2% were Not Otherwise Specified (NOS), Figure 12.

Figure 11 *VLCR 2019 Lung Cancer Type*



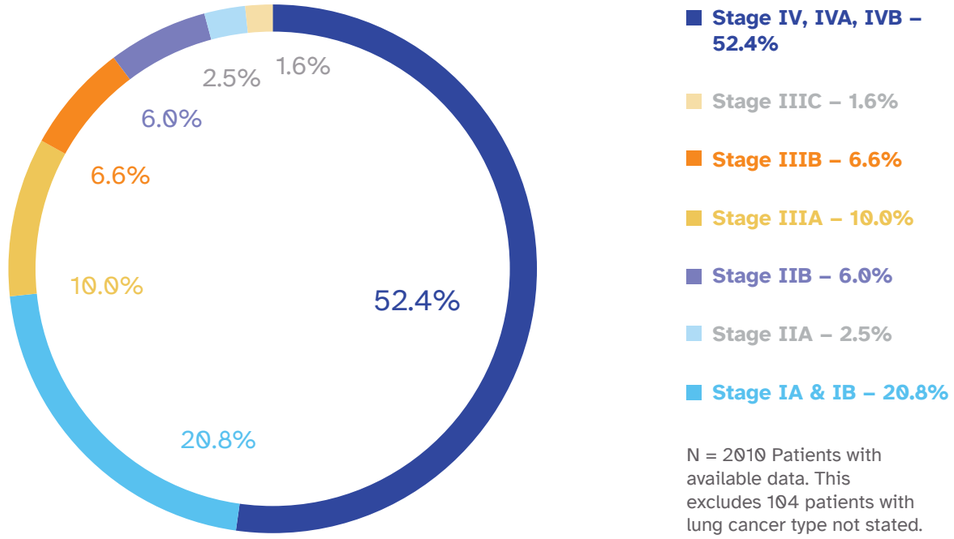
N = 2019 Patients with available data. This excludes 104 patients with lung cancer type not stated.

Figure 12 *VLCR 2019 NSCLC Type*



N = 1719 Patients with Non-Small Cell Lung Cancer

Figure 13 *VLCR 2019 Clinical Staging for NSCLC Type*



N = 2019 Patients with available data. This excludes 104 patients with lung cancer type not stated.

Documentation of clinical stage was not recorded for 193 (11.2%) of the 1,719 NSCLC subjects. Of the 1526 patients with NSCLC and documented clinical stage, the majority had advanced metastatic disease at presentation (Stage IV - 52.4%), while 29.3% had localised, early stage disease (Stage I-II), Figure 13.

> Being a family member of a person with lung cancer and involved in patient advocacy, it is clear that many people feel that their experiences don't receive much attention. The Victorian Lung Cancer Registry is a much needed initiative to better understand what's happening for patients and families, support the development of better services and strengthen the community into the future.

Tom Wood
Lung Cancer Patient Carer and Advocate
VLCR Consumer Representative

VLCR Patient Performance Status In 2019

Table 5 *VLCR 2019 Patient ECOG Status At Diagnosis*

VLCR 2019 PATIENT ECOG STATUS AT DIAGNOSIS

ECOG status at diagnosis	Number	Percent
0—Fully active, able to carry on all normal activity without restriction	522	24.7%
1—Restricted in physically strenuous activity but ambulatory and able to carry out light work	618	29.2%
2—Ambulatory and capable of all self-care but unable to carry out any work activities.	222	10.5%
3—Capable of only limited self-care, confined to bed or chair more than 50% of waking hours	79	3.7%
4—Completely disabled, not able to self-care, totally confined to bed or chair	13	0.6%
Unknown	660	31.2%
Total	**2114**	**100%**

Documentation of performance status was unavailable for n=660 (31.2%) of participants. For those with documented performance status n=1454, 78.4% had good performance status (ECOG 0–I) and n=314 (21.6%) had poor performance status (ECOG ≥ 2), Table 5.

Table 6 *VLCR 2019 Patient Characteristics By Clinical Stage*

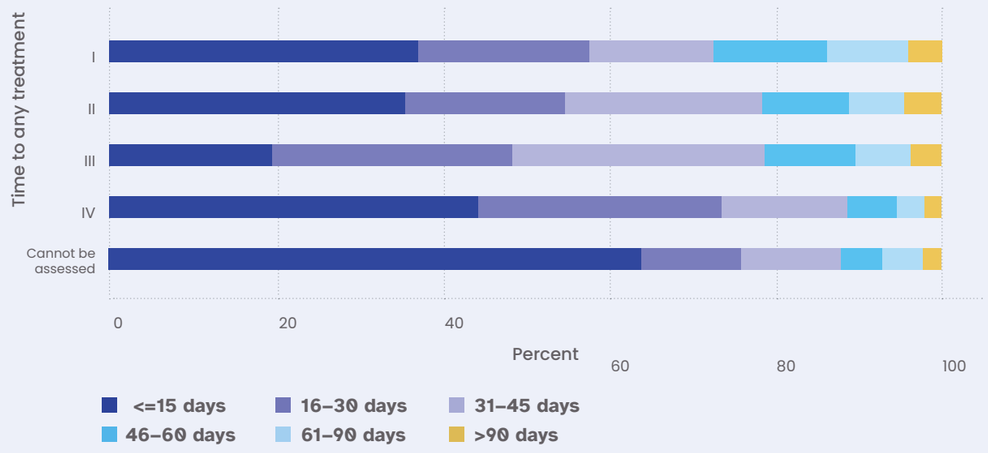
Clinical Stage	I	II	III	IV	Cannot be assessed	Total
VLCR 2019	332	146	319	1045	272	2114
Sex						
Female	164 (49%)	57 (39%)	120 (38%)	453 (43%)	129 (14%)	923 (44%)
Male	168 (51%)	89 (61%)	199 (62%)	592 (57%)	143 (12%)	1191 (56%)
Age						
< 60 years	38 (11%)	13 (9%)	47 (15%)	198 (19%)	42 (12.4%)	338 (16%)
60-69 years	99 (30%)	47 (32%)	112 (35%)	308 (29%)	71 (11.1%)	637 (30%)
70-79 years	143 (43%)	64 (44%)	107 (34%)	343 (33%)	91 (12.2%)	748 (35%)
≥80 years	52 (16%)	22 (15%)	53 (17%)	196 (19%)	68 (17.4%)	391 (19%)
Index of Relative Socio-economic Advantage and Disadvantage (IRSAD)						
81-100% Advantaged	60 (18%)	33 (23%)	56 (18%)	262 (25%)	84 (31%)	495 (23%)
61-80%	58 (17%)	27 (18%)	50 (16%)	221 (21%)	65 (24%)	421 (20%)
41-60%	71 (21%)	29 (20%)	79 (25%)	216 (21%)	52 (19%)	447 (21%)
21-40%	76 (23%)	32 (22%)	55 (17%)	152 (15%)	40 (15%)	355 (17%)
1-20% Disadvantaged	67 (20%)	25 (17%)	79 (25%)	194 (19%)	31 (11%)	396 (19%)
Site Type						
Metropolitan Public	235 (71%)	95 (65%)	202 (63%)	750 (51.3%)	181 (12.4%)	1463 (69%)
Metropolitan Private	29 (9%)	13 (9%)	22 (7%)	83 (42.3%)	49 (25%)	196 (9%)
Regional	68 (20%)	38 (26%)	95 (30%)	212 (46.6%)	42 (9.2%)	455 (22%)
ATSI						
ATSI	0 (0%)	1 (1%)	4 (1%)	13 (65%)	2 (10%)	20 (1%)
Non ATSI	326 (98%)	145 (99%)	312 (98%)	1015 (49.2%)	265 (12.8%)	2063 (98%)
Unknown	6 (2%)	0 (0%)	3 (1%)	17 (54.8%)	5 (16.1%)	31 (1%)
Reviewed at MDM						
No	64 (19%)	20 (14%)	52 (16%)	442 (66%)	91 (13.6%)	669 (31%)
Yes	268 (81%)	126 (86%)	267 (84%)	603 (41.8%)	181 (12.5%)	1445 (69%)

Table 7 *2019 Patient Treatment By Clinical Stage*

Clinical Stage	I	II	III	IV	Cannot be assessed	Total
VLCR 2019	332	146	319	1045	272	2114
Any Treatment*						
Had anti-cancer treatment	316 (95%)	135 (92%)	300 (94%)	811 (78%)	216 (79%)	1778 (84%)
No anti-cancer treatment	16 (5%)	11 (8%)	19 (6%)	234 (22%)	56 (21%)	336 (16%)
Systemic Anti-Cancer treatment**						
Yes	38 (11%)	67 (39%)	229 (72%)	645 (62%)	91 (33%)	1070 (50%)
No	288 (87%)	67 (58%)	81 (25%)	340 (33%)	170 (63%)	946 (45%)
Declined	6 (2%)	12 (3%)	9 (3%)	60 (5%)	11 (4%)	98 (5%)
Radiotherapy treatment						
Yes	101 (30%)	57 (5%)	251 (79%)	564 (54%)	85 (31%)	1058 (50%)
No	222 (67%)	84 (8%)	67 (21%)	442 (42%)	180 (66%)	995 (47%)
Declined	9 (3%)	5 (8%)	1 (0.3%)	39 (4%)	7 (3%)	61 (3%)
Surgical Resection						
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 *2019 Time From Diagnosis To Treatment By Stage*



Patients with clinical stage "Cannot be assessed" who had treatment (n=216), n=126 (58%) had a surgical resection.

Clinical Quality Indicators

The VLCR collects and reports on data relating to 20 clinical quality indicators. The VLCR clinical quality indicators have been developed by an expert working group (see Appendix D).

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 data can be benchmarked as funnel plots. When interpreting funnel plots (see example plot Figure 15), the horizontal axis (x-axis) measures the number of cases being examined, or in this report the number of patients at the recruiting hospital for the particular indicator. The vertical axis (y-axis) measures the percentage of cases that meet the clinical indicator being reported.

For example, in the example below, a point estimate (represented by the coloured dot) plots the number of cases by percentage of cases meeting the indicator for each recruiting hospital contributing to VLCR. The larger the number of cases (volume), the further to the right will be the hospital'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 health services combined. As the number of patients gets larger statistical power increases, thus the 95% and 99.8% control limits (red dashed lines) narrow towards the pooled average. Dots that fall outside the 99.8% control limits are deemed statistical outliers, however clinical judgement surrounding the reported indicator must be used to assess whether a hospital is a true outlier.

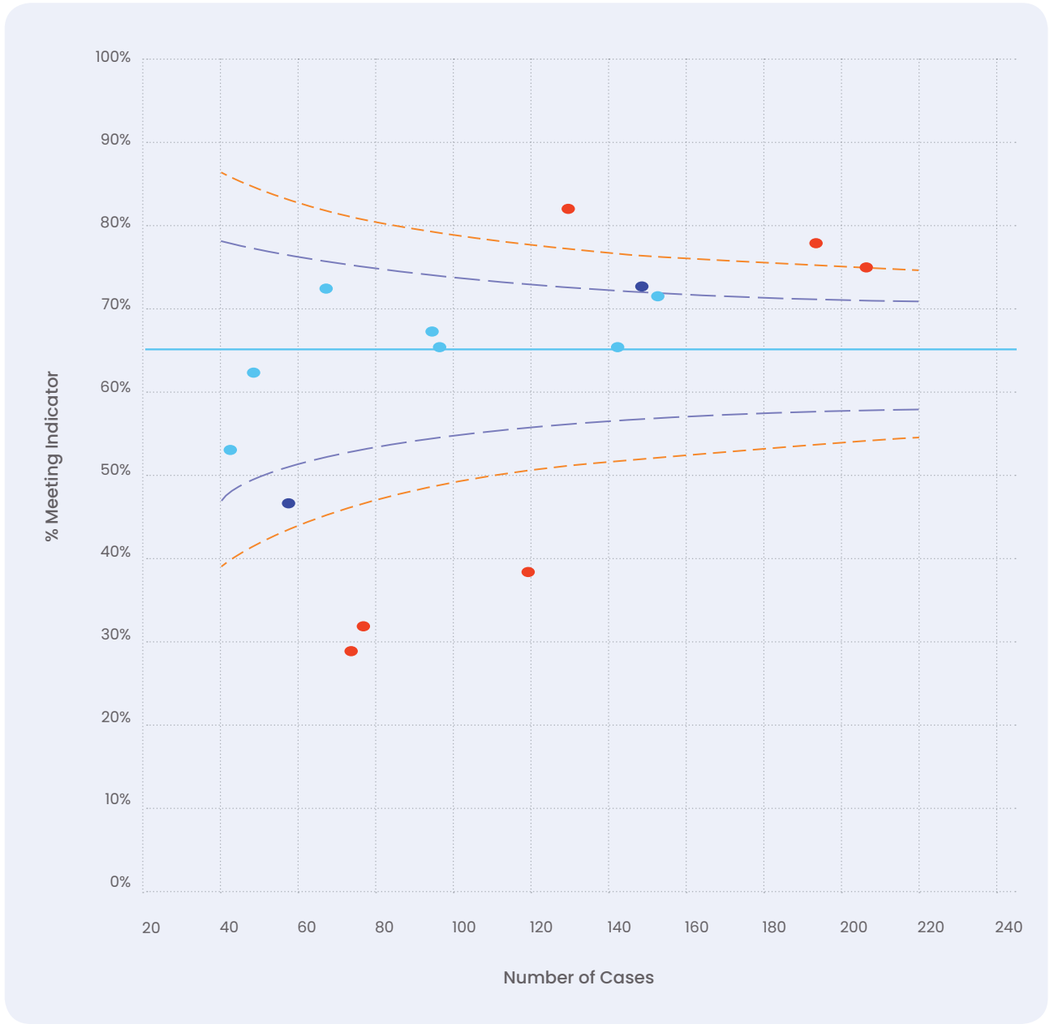
Risk adjustment: This report includes risk-adjusted funnel plot analysis because VLCR is an observational study design and we wanted to account for potential confounders. Patient sex, age, and clinical stage were determined to be clinically important and included in all risk-adjusted funnel plots except where otherwise specified for reasons such as collinearity, low numbers meeting the indicator, or small sample size.

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.

Colour dots are used to indicate if a site is within 2SD or 3SD of the cohort mean

- **Within 2SD or 95% control limit**
- **Within 3SD or 99.8% control limit**
- **Outside 3SD or 99.8% control limit**

Figure 15 *Funnel Plot Example*



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

Within Limits | Outside 95% Limit | Outside 98.8% Limit | 95% Limit | 99.8% Limit IV

SELECTED QUALITY INDICATORS

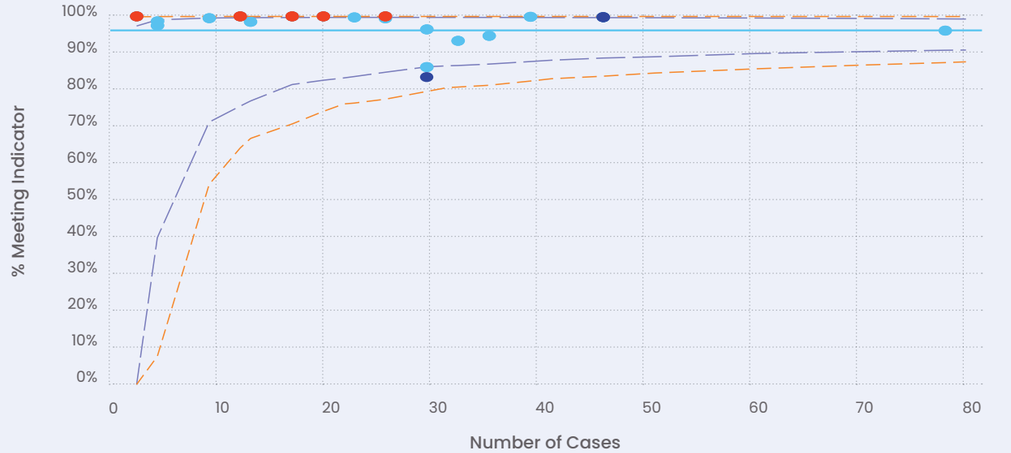
The following quality indicators are grouped to reflect six specific aims to improve core quality of health by delivering health care that is: safe, effective, patient-centered, timely, efficient and equitable [14].

Appendix E lists data used to calculate each quality indicator. Funnel plots risk adjust for sex, age, birthplace 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 a coloured-dot according to site performance.

Safe Health Care

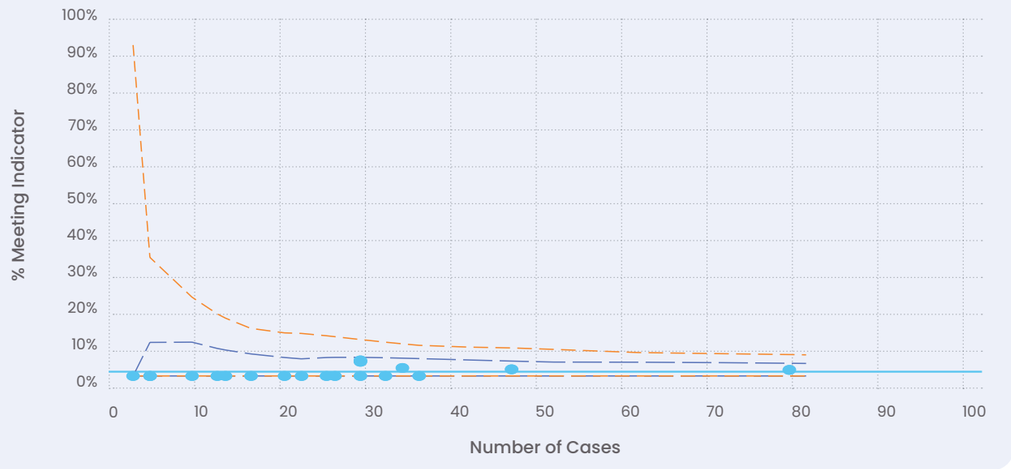
Safety in Healthcare may be defined as the, **'Degree to which health care processes avoid, prevent, and ameliorate adverse outcomes or injuries that stem from the process of health care itself'** [14]. Two indicators have been chosen to reflect patient safety. First, the utilisation of PET scanning 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 = 463: Total cohort mean 96%.
Note: 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)*

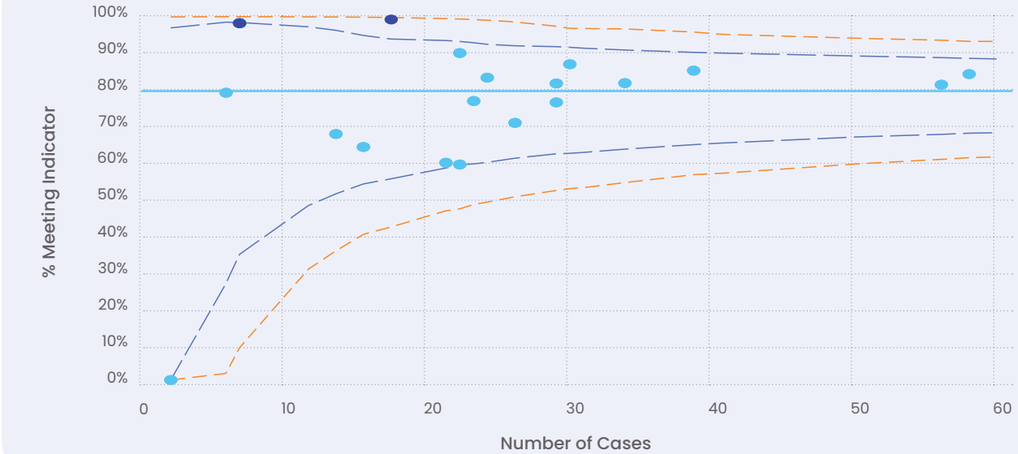


N = 450: Total cohort mean 2%.
Note: Risk adjusted for patient sex, age and clinical stage. The use of this funnel plot to identify potential outliers must be made with caution due to small numbers. In this funnel plot, sites with no deaths recorded are below the blue line (pooled average). Sites above 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 26).

Effective Health Care

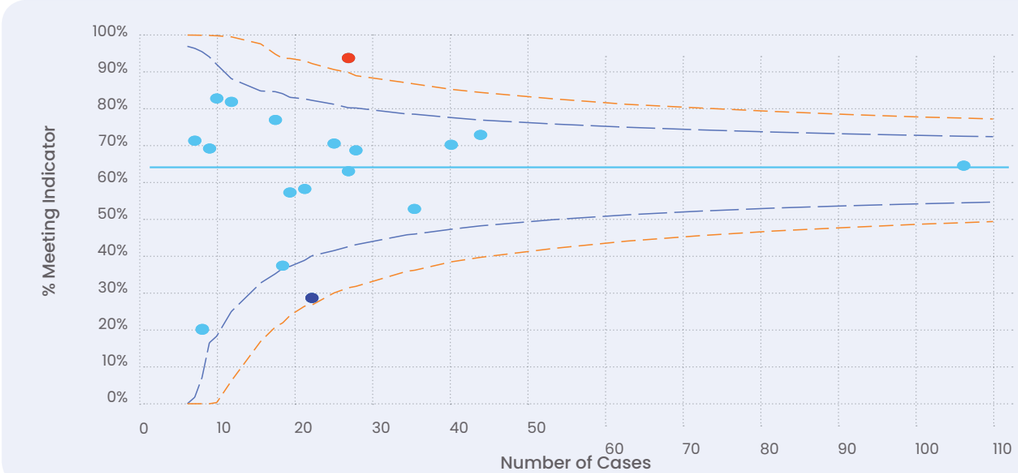
Effective healthcare may be defined as, **'The extent to which improvements in health care are attained, using available evidence-based healthcare measures'** [14]. Two indicators have been chosen to reflect healthcare effectiveness. First, the proportion of clinically appropriate patients in whom chemotherapy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

Figure 18 *Proportion of patients with NSCLC (clinical stage IIIB and IV) with ECOG (0-1) who have commenced chemotherapy (Quality Indicator 17)*



N = 472. Total cohort mean 81%.
Note: 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)*

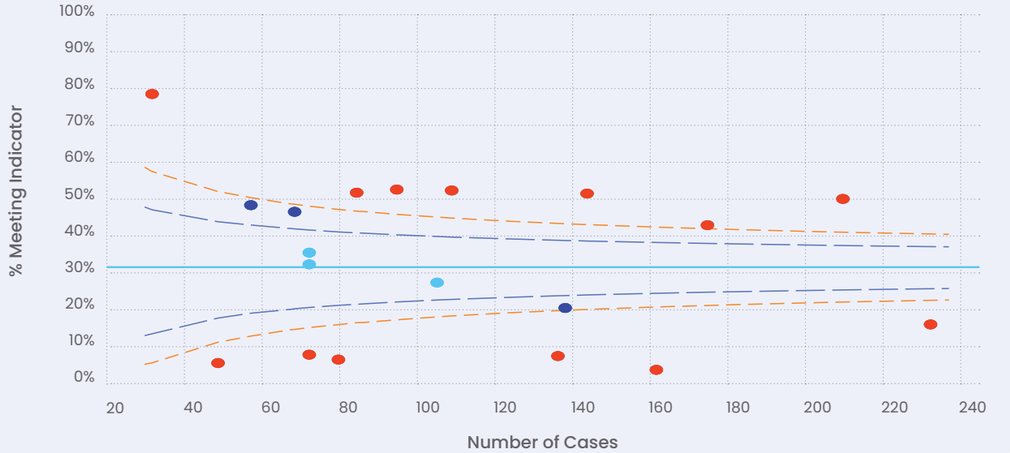


N = 447. Total cohort mean 63%.
Note: The use of this funnel plot to identify potential outliers must be made with caution due to small numbers.

Patient-Centred Health Care

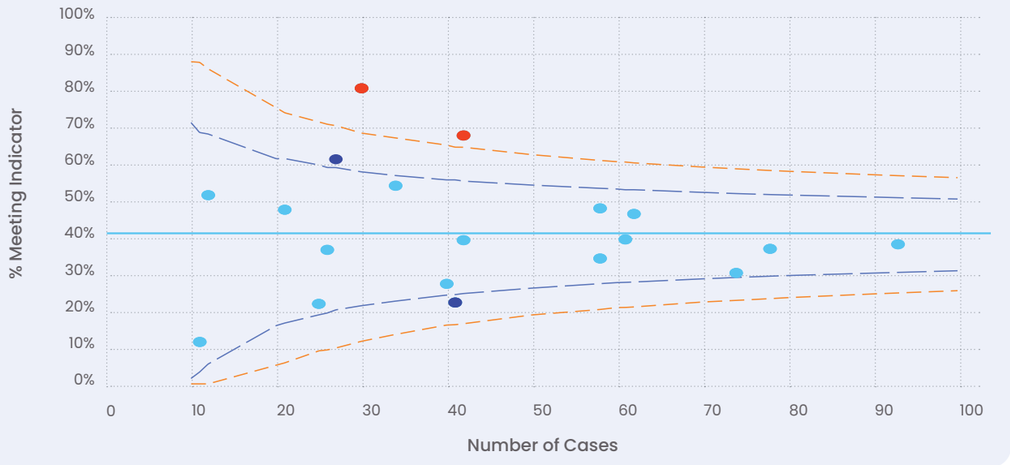
Patient-centred healthcare may be defined as, **'Providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions'** [14]. Two indicators have been chosen to reflect patient-centred healthcare. First, 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= 2114. Total cohort mean 31%

Figure 21 *Proportion of patients with NSCLC (stage IV) referred to any palliative care services within 8 weeks of diagnosis (Quality Indicator 20)*

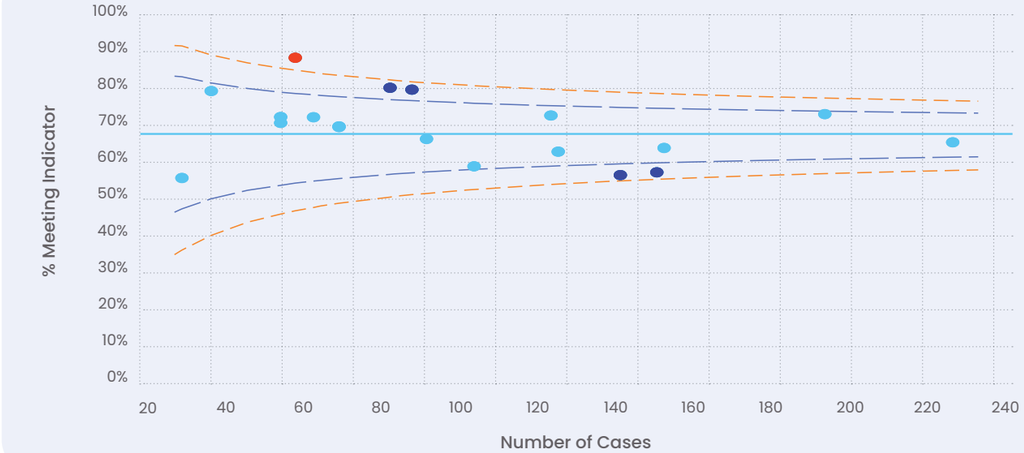


N = 797. Total cohort mean 41%.
Note: The use of this funnel plot to identify potential outliers must be made with caution due to small numbers .

Timely Health Care

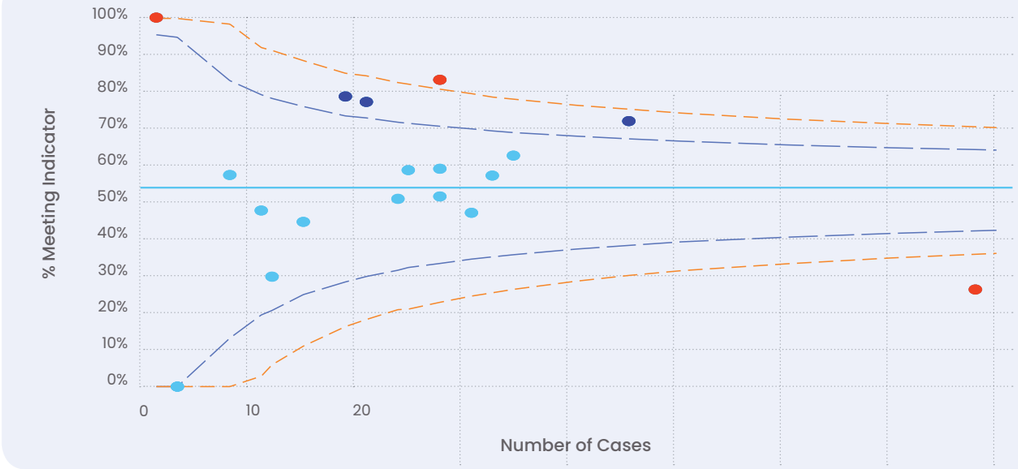
Timely healthcare may be defined as, **'Providing care within accepted time limits, after recognising the need for care. This includes the time interval to being seen by a doctor, and the time interval between identifying a need for specific tests and treatments and actually receiving the services'** [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 = 1,968. Total cohort mean 69%.
Note: 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)*

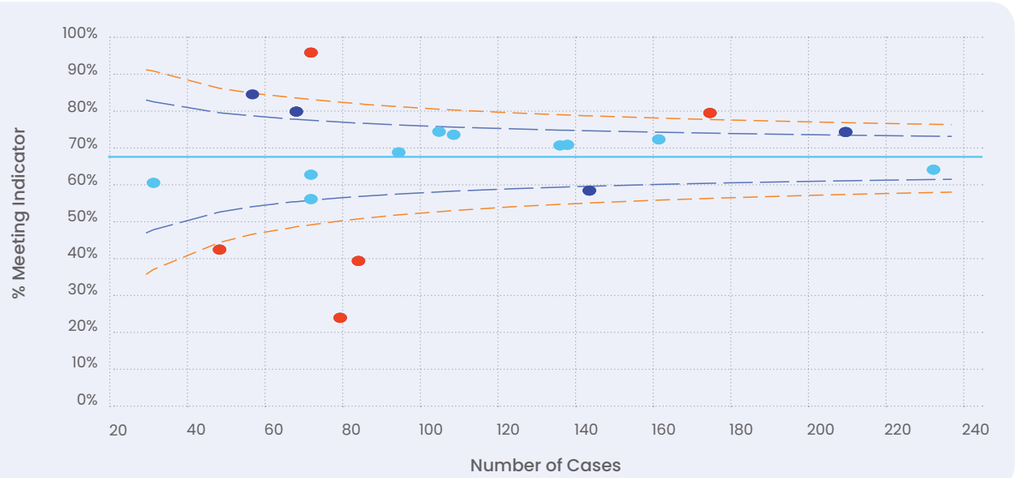


N = 450. Total cohort mean 54%.
Note: Surgical resection includes pneumonectomy, lobectomy, segmentectomy and wedge resection. The use of this funnel plot to identify potential outliers must be made with caution due to small numbers.

Efficient Health Care

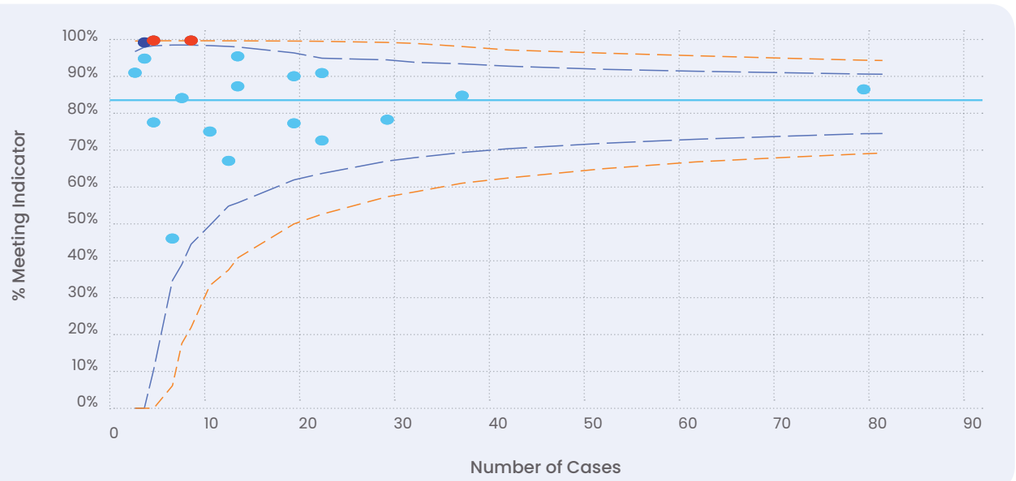
Efficient healthcare may be defined as, **'Optimal use of available resources to yield maximum health benefits'** [14]. Two indicators have been chosen to reflect efficiency of healthcare. First, the proportion of subjects for whom there is evidence of presentation to a multidisciplinary meeting, and 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 (MDM) documented (Quality Indicator 9)*



N = 2,114. Total cohort mean 69%.

Figure 25 *Proportion of patients with NSCLC who have undergone a surgical resection and clinical stage agrees with pathological stage (Quality Indicator 11)*



N = 294. Total cohort mean 83%.
Note: The use of this funnel plot to identify potential outliers must be made with caution due to small numbers.

Within Limits | Outside 95% Limit | Outside 98.8% Limit | 95% Limit | 99.8% Limit IV

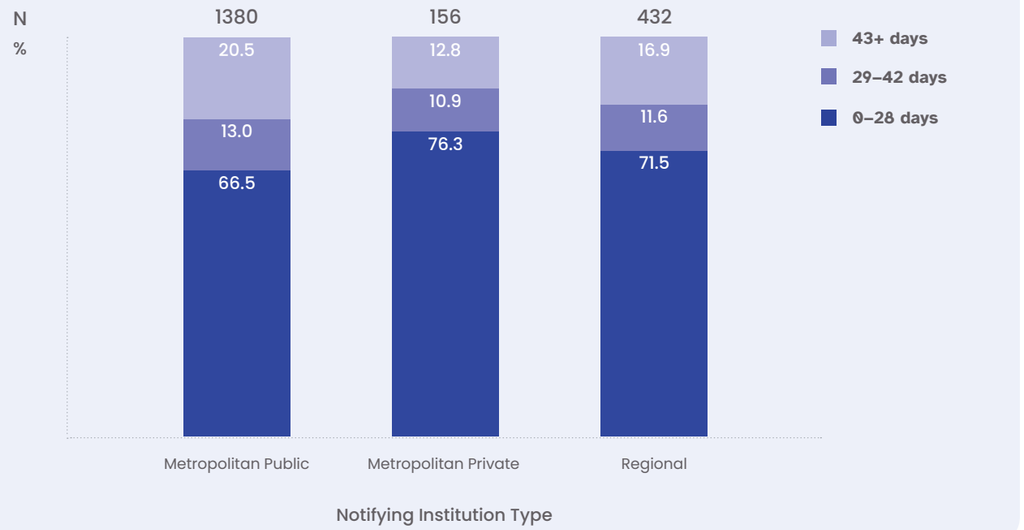
> Lung Foundation Australia strongly supports a unified national clinical quality registry to better inform lung cancer care and treatment. Access to timely, reliable and quality data will continue to drive reform of health care for lung cancer patients particularly with a national Targeted Lung Cancer Screening program on the horizon.

Mark Brooke
CEO, Lung Foundation Australia

Equitable Health Care

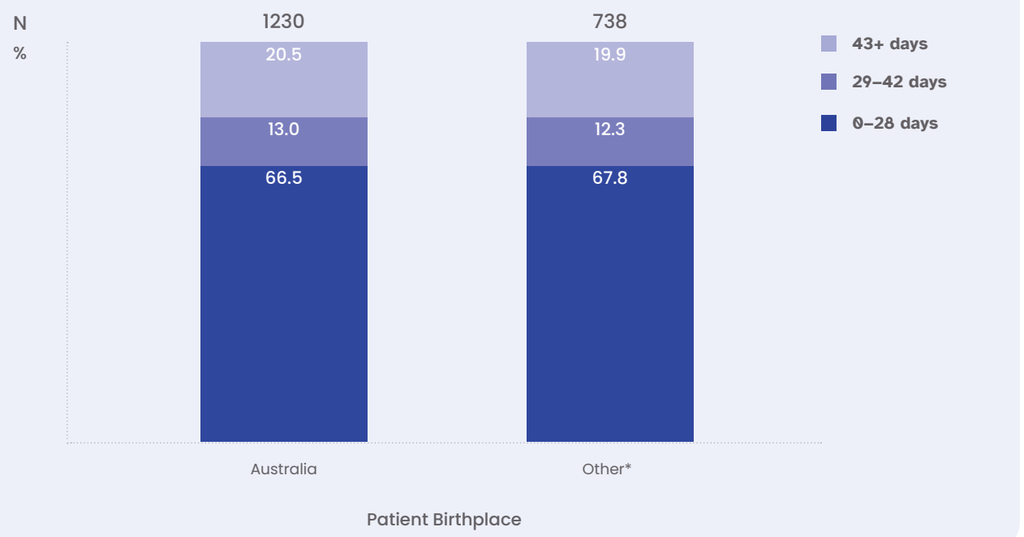
Equitable healthcare may be defined as, **'Equal distribution of healthcare and its benefits, regardless of gender, ethnicity, geographic location or socio-economic status'** [14].

Figure 26 *Referral to diagnosis interval by health service*



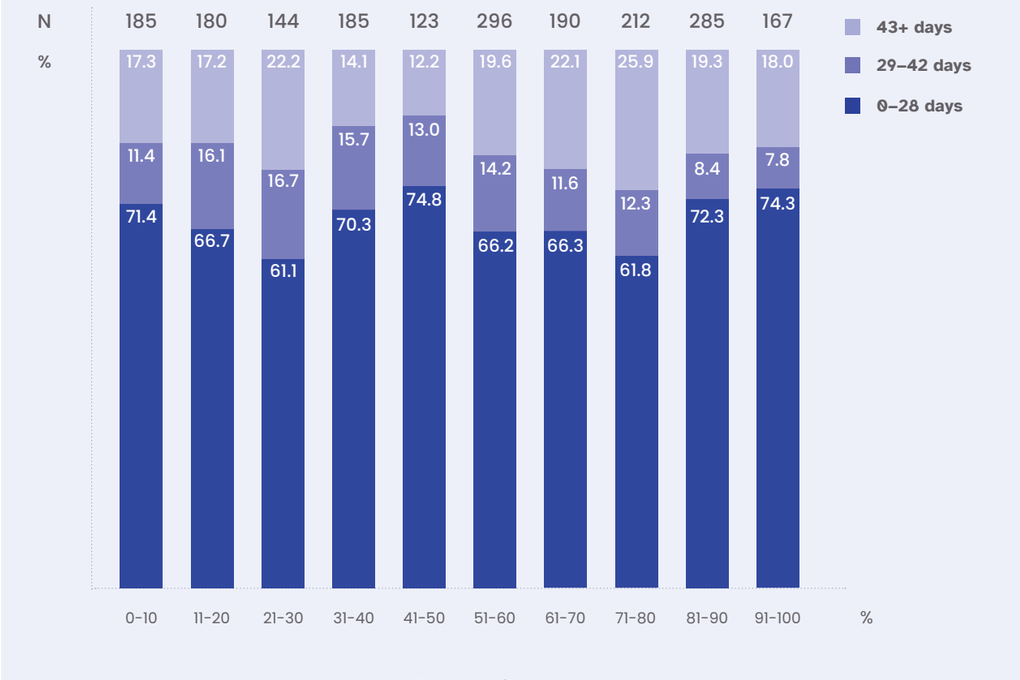
Pearson's chi–squared test: p–value = 0.053

Figure 27 *Referral to diagnosis interval by birthplace*



Pearson's chi–squared test: p–value = 0.78
*Other includes 2 patients with unknown country of birth

Figure 28 *Referral to diagnosis interval by Socio-economic status*



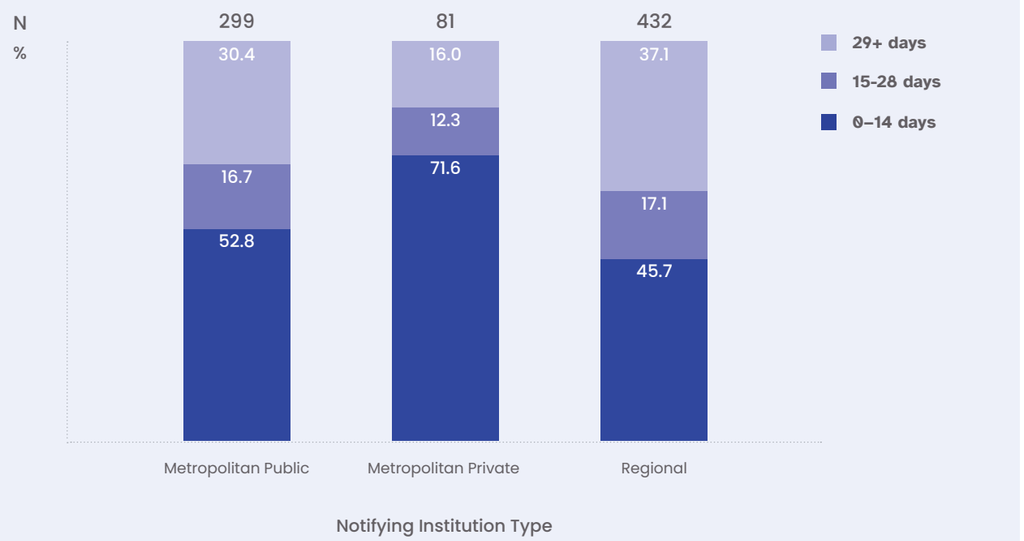
Pearson's chi–squared test: p–value = 0.26
IRSAD 0-10% denotes most socio-economically disadvantaged/least advantaged
IRSAD 91-100% denotes most socio-economically advantaged/least disadvantaged

A comparison of time from referral to diagnosis by type of institution shows that Metropolitan Public hospitals had a lower proportion of patients achieving timely diagnosis (within 28 days from referral) when compared to Metropolitan Private and Regional hospitals, Figure 26 (66.5 vs 76.3 and 71.5, p=.053).

There was no difference in the proportion of Australian born and non-Australian born patients diagnosed within 28 days of referral (Figure 27, 68.8% vs 67.8% p=0.78).

The time interval from referral to diagnosis by socio-economic status is similar across all groups. The most advantaged group (91-100%) has the highest proportion of patients with rapid diagnosis (within 28 days of referral), 74.3% and the 21-30% group has the lowest proportion of patients with rapid diagnosis (61.1% Chi2 p=0.02) (Figure 28).

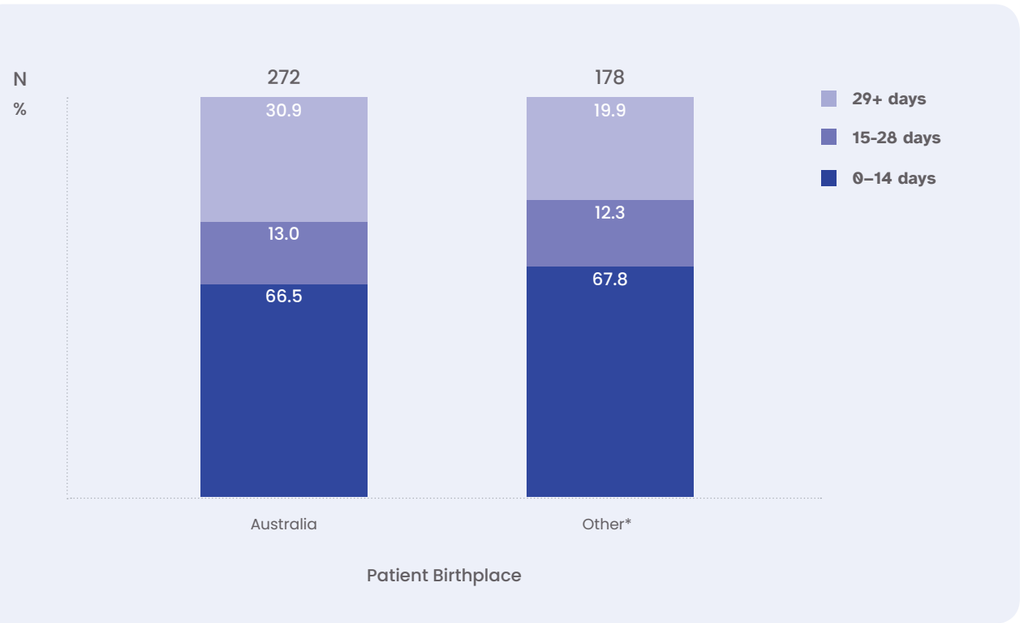
Figure 29 *Diagnosis to surgical resection interval by health service*



Pearson's chi–squared test: p–value 0.02

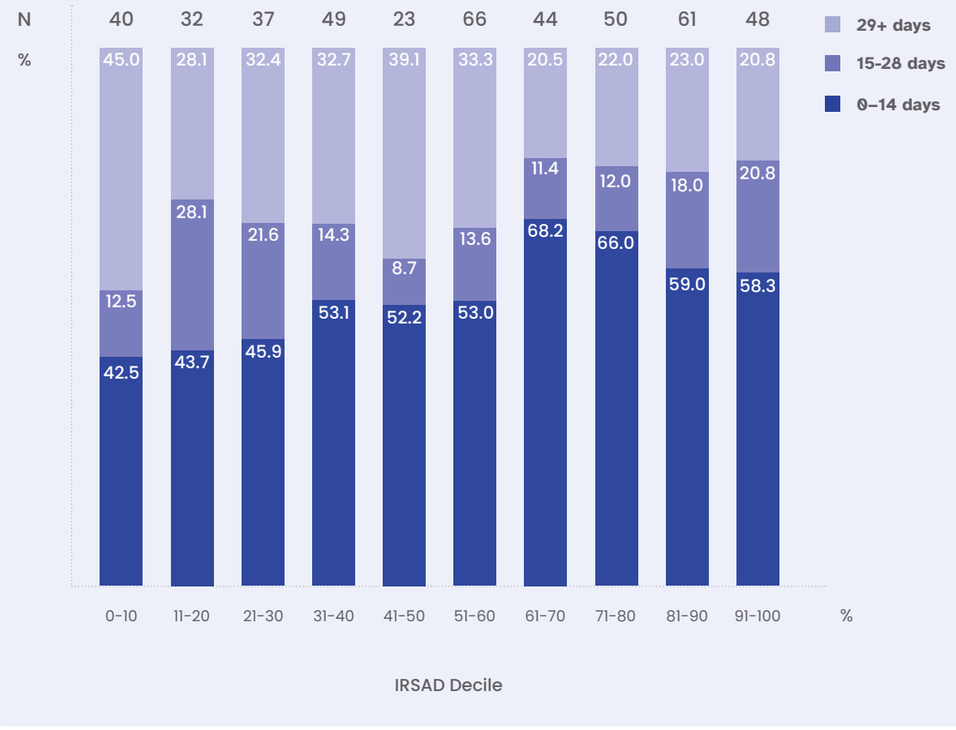
Patients are presented by the institution responsible for diagnosis, which may not be where surgical resection occurred. For example, patients diagnosed in a regional institution may have had their surgical resection at a Metropolitan Public or Private hospital.

Figure 30 *Diagnosis to surgical resection interval by birthplace*



Pearson's chi–squared test: p–value = 0.50
*Other includes 13 patients with unknown country of birth

Figure 31 *Diagnosis to surgical resection interval by socio-economic status*



Pearson's chi–squared test: p–value = 0.26
IRSAD 0-10% denotes most socio-economically disadvantaged/least advantaged
IRSAD 91-100% denotes most socio-economically advantaged/least disadvantaged

A higher proportion of patients from Metropolitan Private institutions are resected within 14 days of diagnosis compared with patients from Metropolitan Public or Regional institutions (71.6% vs 52.8% vs 45.7% respectively p = 0.02), Figure 29. A higher proportion of regional patients have delayed time to resection compared to metropolitan public and metropolitan private hospitals (37.1% compared to 30.4% and 16% respectively), p=0.02.

The timeliness of surgical resection for patients by county of birth shows is not dissimilar for Australian and non-Australian born patients (53.3%, Other 57.9%, p = 0.50), Figure 30.

The time interval by socio-economic status indicates patients in the higher decile (91-100%, most advantaged) have a higher proportion of patients with a surgical resection within 14 days of diagnosis, compared to most disadvantaged (0-10%) (58.3% vs 42.5%, p = 0.26). A higher proportion of the most disadvantaged patients (0-10%) have delayed time from diagnosis to resection compared to the most advantaged group (45% vs 20.8%), p=.26. Figure 31.

Appendices

APPENDIX A *List Of Figures*

APPENDIX B *List Of Tables And Glossary*

GLOSSARY

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

APPENDIX C *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 registry. Data quality measures are reported regularly to the Management Committee.

Steering Committee Responsibilities:

Develop and ensure registry meets overall objectives

Facilitate policy support for issues identified by the Management Committee

Establish an outlier policy and ensure that it is enacted

Ensure the Management Committee meets its reporting obligations to hospitals, clinicians and working groups

Review and advise on registry output

Establish data access policy and ensure that is enacted

Monitor data quality management processes

Review and provide advice on communication strategy

Steering Committee Comprises Senior Clinicians:

Representation from:

Clinician stakeholders

Epidemiology

Victorian Cancer Registry

Department of Health

Professional society/ies

Consumer representative

Management Committee Comprises:

At least 2 clinical specialists

At least 2 members of the data management unit

Date custodian

Management Committee Responsibilities:

Management of staff, work duties and budget

Ensure that data collection & quality processes function effectively

Ensure data issues are managed in a timely and effective manner

Arrange for timely and appropriate statistical analyses

Ensure compliance with requirements of ethics committees and legislation

Provide reports to steering committee

Liaise with funding bodies and stakeholders

Provide support for the function of the various scientific working groups

Scientific Working Groups

Comprises clinicians with interest in area and ≥ 1 member of the data management centre

Report to the Management Committee

Submit report/s to steering committee as agreed

Data Management Unit

Comprises registry data custodian and data collectors

Report to the Management Committee

APPENDIX D *VLCR Steering Committee Membership In 2019*

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 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 patients with documented presentation at a lung MDM	Number of patients in Registry
10	Number of patients undergoing resection with clearly documented PET scan	Number of patients undergoing resection
11	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
Tissue Diagnosis Indicator		
12	Number of patients with confirmed tissue diagnosis (malignant cytology or histology)	Number of patients in Registry
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 who have had a surgical resection and died within 30 days of surgery	Number of patients with NSCLC who have undergone surgical resection
15	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
16	Number of patients receiving anti-cancer treatment (surgery, radiotherapy, chemotherapy or biological therapy)	Number of patients in Registry
17	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)
18	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
19	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		
20	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)

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.

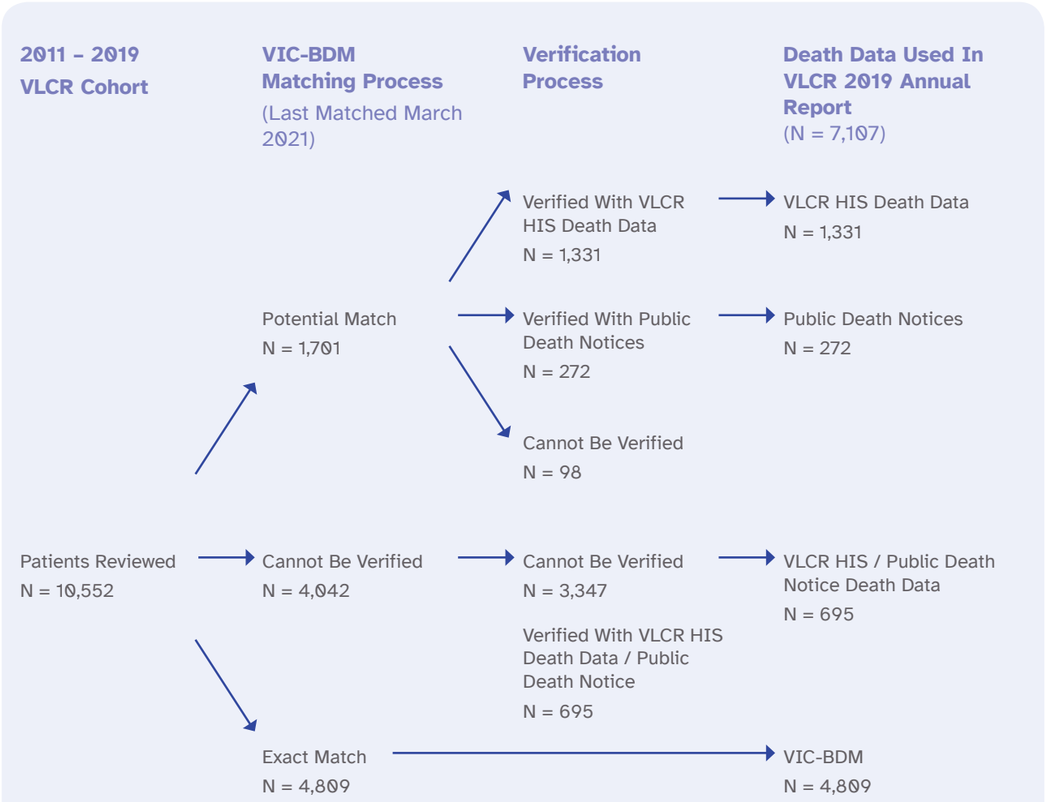
Case ascertainment for VLCR will occur via notification by participating site Health Information Systems (HIS) of hospital discharges confirming ICD 10 coding identifying lung cancer as the principal reason for admission. Prevalence cases are discarded and incident cases are reviewed for inclusion and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

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. Cancer Council Victoria, Statistics & Trends 2018. Cancer Council Victoria November, 2019

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, “The State of Patient Safety and Quality in Australian Hospitals 2019” ACSQHC, 2019, pg 66

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 21st centurruy” (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*

1. Forecasting of Lung Cancer Incident Cases at the Small-Area Level in Victoria, Australia. Win Wah, Rob G Stirling, Susannah Ahern, Arul Earnest Int J Environ Res Public Health 2021 May 11;18(10):5069

2. Measurement properties of the 12-item Short Form Health Survey version 2 in Australians with lung cancer: a Rasch analysis Sze-Ee Soh, Renata Morello, Darshini Ayton, Susannah Ahern, Ri Scarborough, Claire Zammit, Margaret Brand, Robert G Stirling, John Zalcberg Health Qual Life Outcomes 2021 May 31;19(1):157Excess mortality and undertreatment in elderly lung cancer patients: treatment nihilism in the modern era? Jonathan Pham, Matthew Conron, Gavin Wright, Paul Mitchell, David Ball, Jennifer Philip, Margaret Brand, John Zalcberg, Rob G Stirling

3. Effect of follow-up surveillance after curative-intent treatment of NSCLC on detection of new and recurrent disease, re-treatment and survival: A systematic review and meta-analysis. Stirling, RG, Chau, C, Shareh, A, Zalcberg J and Fischer, M JTO 2020 2021 Feb 12;S1556-0864(21)01669-5

4. Impacts of multidisciplinary meeting case discussion on palliative care referral and end-of-life care in lung cancer: A retrospective observational study. Sridharan K, Paul E, Stirling RG, Li C. Intern Med J. 2021 Jan 18. doi: 10.1111/imj.15215

5. Influence of timeliness and receipt of first treatment on geographic variation in non-small cell lung cancer mortality. Wah W, Stirling RG, Ahern S, Earnest A. Int J Cancer. 2020 Oct 12. doi: 10.1002/ijc.3334

6. Association between Receipt of Guideline-Concordant Lung Cancer Treatment and Individual- and Area-Level Factors: A Spatio-Temporal Analysis. Wah W, Stirling RG, Ahern S, Earnest A. Cancer Epidemiol Biomarkers Prev. 2020 Dec;29(12):2669-267

7. The Victorian Lung Cancer Service Redesign Project: Impacts of a Quality Improvement collaborative on timeliness and management in lung cancer. Geraldine L, Peter B, Heather D, Craig U, Cara R, Kellie H, Robert B, Carol P, Christal G, Phillip P, Brooke T, Javier T, Carole M, Cheryl L, Margaret B, Arul E, Breanna P, Marita R, John Z, Rob Stirling. Intern Med J. 2020 Sep 8. doi: 10.1111/imj.15043

8. Hospital lung surgery volume and patient outcomes. Stirling R, Stenger M, Zalcberg J. Lung Cancer. 2020 Apr;142:138-139

9. Peeling the Onion of Health Care Disparity in Lung Cancer. Stirling R, Zalcberg J. J Thorac Oncol. 2019 Aug;14(8):e167-e168

10. FDG-PET follow up of Non-Small Cell Lung Cancer: Not dead yet. Stirling RG, Zalcberg J. Ann Thorac Surg. 2019 Jul 6. pii: S0003-4975(19)30993-2

11. Lung cancer prognostic index: a risk score to predict overall survival after the diagnosis of non-small-cell lung cancer. Alexander M, Wolfe R, Ball D, Conron M, Stirling RG, Solomon B, MacManus M, Officer A, Karnam S, Burbury K, Evans SM. Br J Cancer. 2017 Aug 22;117(5):744-751

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

13. 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

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

15. 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

16. 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

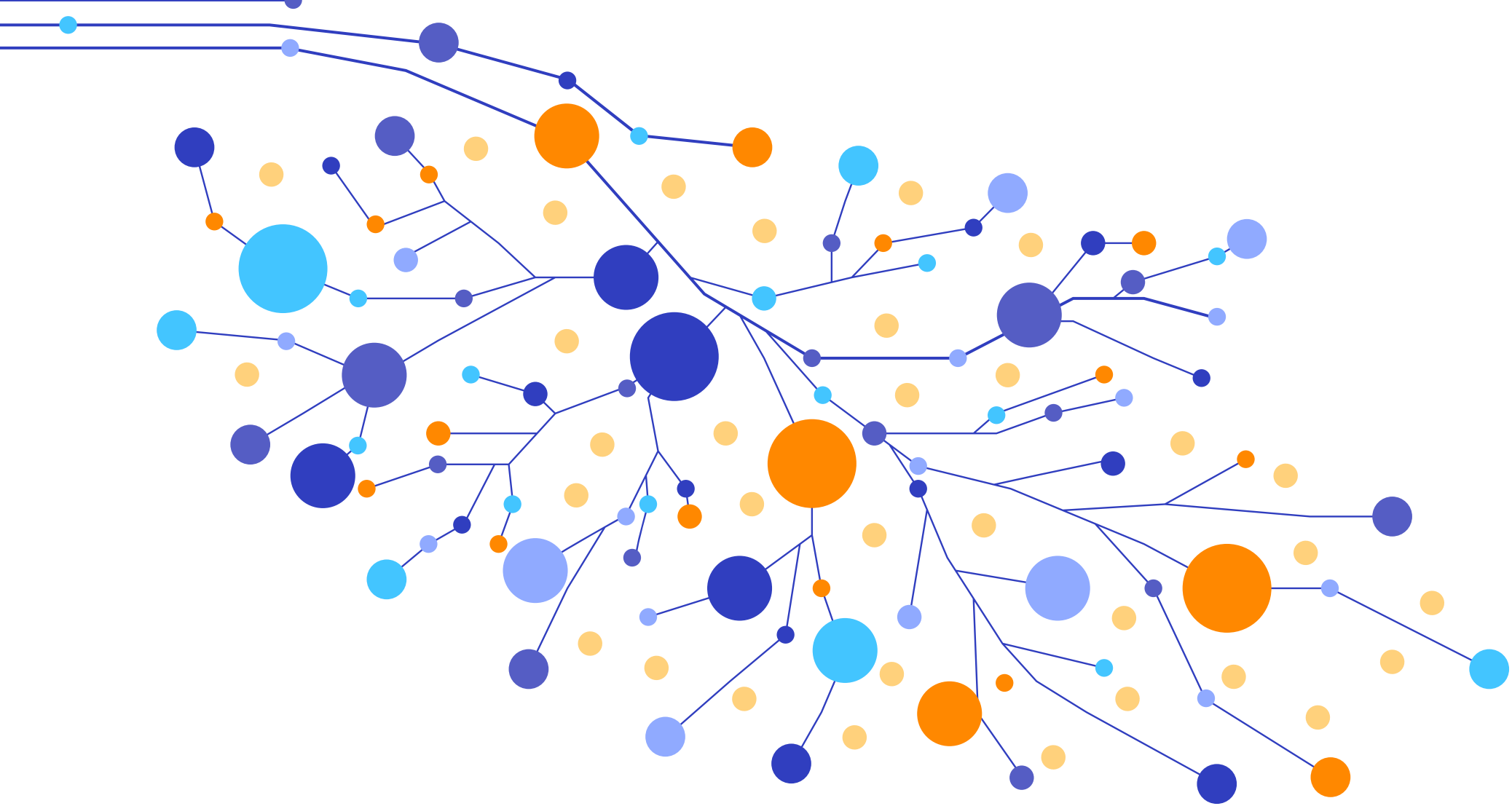
17. Clinical quality registries: engaging effectiveness data for quality improvement. Stirling RG. Am J Public Health. 2014 Dec;104(12):e10

18. 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

19. 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

20. 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

21. 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



Annual Report 2019