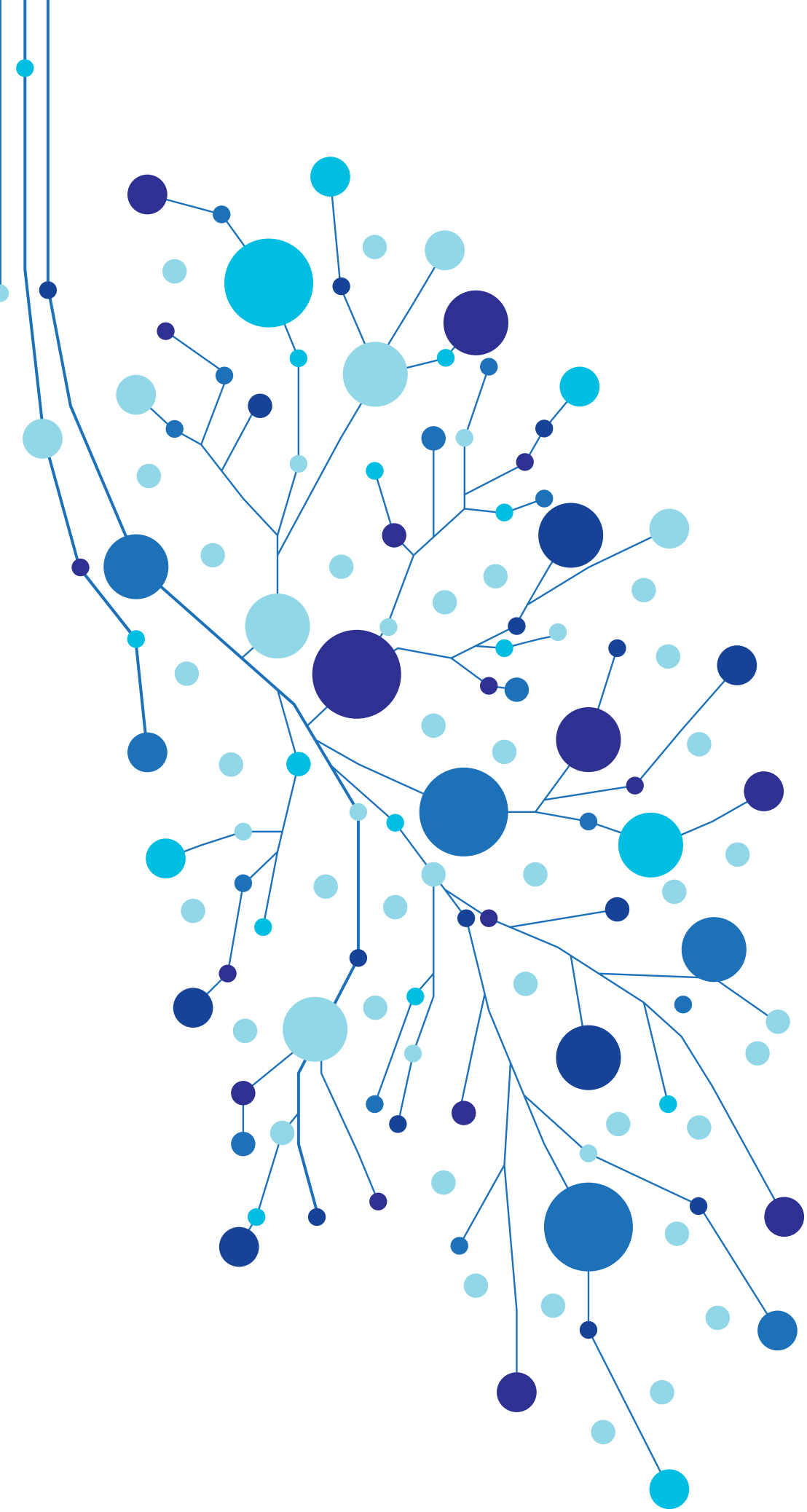
Victorian Lung Cancer Registry

Annual Report 2021



VLCR Victorian Lung Cancer Registry

MONASH University

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

www.vlcr.org.au

Victorian Lung Cancer Registry Monash University
Level 5 553 St Kilda Rd Melbourne VIC 3004
Phone: +61 3 9903 0206
Email: med-cancerregistries@monash.edu

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Contents

Foreword & Executive Summary

It is with great pleasure that I present the Victorian Lung Cancer Registry (VLCR) Annual Report for patients diagnosed with a primary lung cancer from January -December, 2021.

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 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.

VLCR reporting provides institutional benchmarking that enables the identification of significant unwarranted variation from clinical practice guidelines in process and outcomes between participating institutions. These findings identify multiply potential targets and opportunities for Quality Improvement in lung cancer management at stakeholder institutions.

The VLCR reports a number of clinical quality indicators that measure compliance with agreed best practice. The 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.

Associate Professor Rob Stirling, MBBChBAO, MPH, FISQua, FRCPI, FRACP

Coordinating Principal Investigator, Steering Committee Chairman Victorian Lung Cancer Registry

Whilst in 2021 the VLCR population capture is over 80% of all eligible 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.

2021 was a very challenging in the Victorian healthcare system with 4 COVID lockdown periods totalling 98 days. These lockdowns caused major disruptions for both in-patient and out-patient care and placed health care workers under significant strain in the workplace. The VLCR remains greatly appreciative of the work done throughout the healthcare system by hospital governance, administrators, nurses, doctors, allied health and support staff who managed to keep the doors open during this very challenging period.

The VLCR is committed to providing reports that fulfill the needs of key stakeholders. To provide feedback, or requests for access to the aggregated dataset, please email med-vlcr@monash.edu. For more information about the VLCR governance, data items collected, data specifications, research and publications please refer to the website www.vlcr.org.au

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 are all patients who present with secondary lung cancer, mesothelioma, 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, providing information about the Registry, their involvement, and what data will be collected. Invitees are given two weeks to 'opt- out' of the Registry before collection of demography and clinical data commences. Patients have the option to withdraw their consent to participate at any time.

The VLCR data collection process can be described in the following stages. See Appendix E for the VLCR participant and data transfer workflow.

Stage 1

Patients with a principal diagnosis of lung cancer are currently identified through coded admissions data (ICD-10-AM) at participating sites. The medical record is then reviewed to identify the health status and diagnosis date 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. Administrative data is used for demographics and clinical data. Additional clinical data that is not available from administrative datasets is collected from the medical records. Linked datasets are used to report death dates.

Stage 3

Collection of patient-reported outcomes and experiences of care has been piloted in a VLCR-sub study, results to be published later in 2023.

2021 The Year In Numbers

01. Registrations

2,159
New registrations in 2021

27
Opted out in 2021

15,261
Total registrations to December 2021

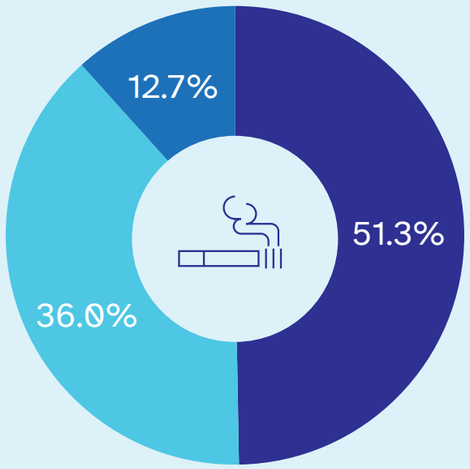
02. Demographics

Male
= 55.1%

Aboriginal and Torres Strait Islander
= 0.93%

Participants aged 70 and older
= 56.2%

ECOG
Participants with an ECOG <2
= 53.2%



- Ex-smoker
- Current smoker
- Never smoked

N = 2,148 Patients with available data. This excludes 141 patients with smoking status not stated.

03. Clinical stage

I-II
Participants with Stage I – II disease
= 25.6%

III-IV
Participants with Stage III – IV
= 60.5%

Unknown Clinical Stage
= 13.9%

04. Treatment

Lung Cancer Resection	Systemic Anti-Cancer Therapy (SACT)	Radiotherapy	No treatment
24.3%	47.6%	40.8%	18.0%

Note: Some patients will be included in more than one treatment modality during the data collection period

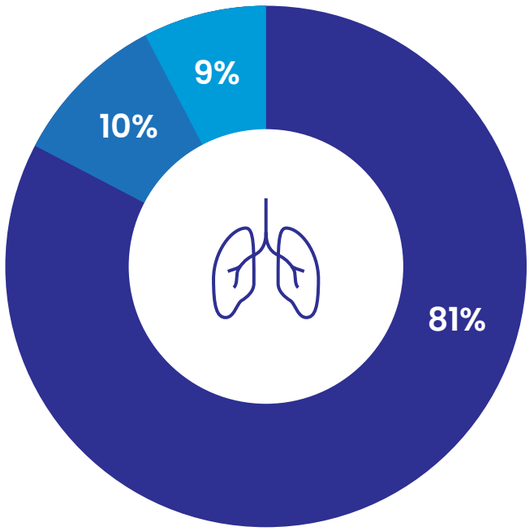
05. Participation

50
Participating institutions

640
Participating clinicians

2021 Lung Cancer Type

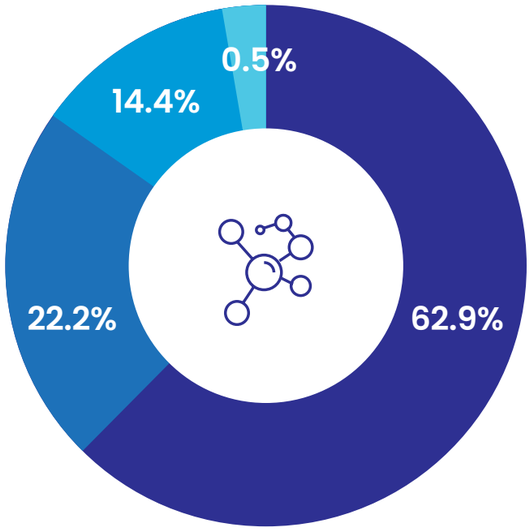
Figure 1A: ***Lung cancer types in 2021***



- Non-small Cell Lung Cancer (NSCLC) – n=1,743 (81%)
- Small Cell Lung Cancer (SCLC) – n=211 (10%)
- Not available / Other Lung Cancer – n=205 (9%)

NOTE: Total number of participants = 2,159

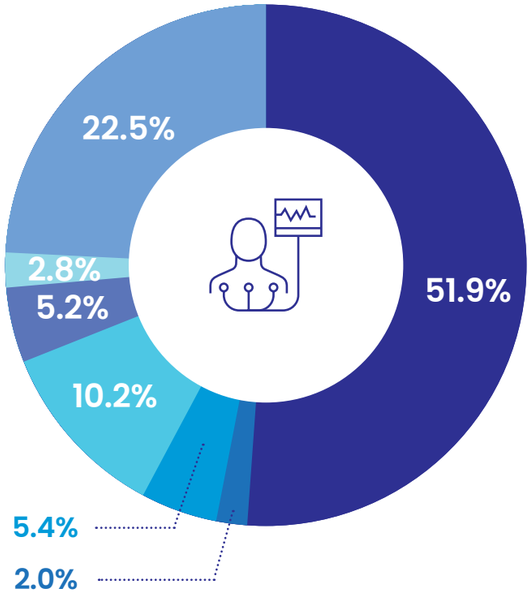
Figure 1B: ***NSCLC sub-types in 2021***



- Adenocarcinoma - n= 1097 (62.95%)
- Squamous cell carcinoma - n=386 (22.14%)
- Large cell carcinoma - n=10 (0.57%)
- Not specified - n=250 (14.34%)

NOTE: Total number of participants = 1,743

Figure 2: ***NSCLC clinical stage at diagnosis in 2021***



- Stage IV, IVA, IVB - 51.9%
- Stage IIIC - 2.0%
- Stage IIIB - 5.4%
- Stage IIIA - 10.2%
- Stage IIB - 5.2%
- Stage IIA - 2.8%
- Stage IA & IB - 22.5%

NOTE: Patients with Non-small Cell Lung Cancer and available clinical stage, n=1,519

2021 Total Cohort Characteristics By Clinical Stage

Clinical stage is collected by reviewing clinical test results, medical correspondence and multidisciplinary team meeting (MDM) notes. The following graphs present patient demographics and treatment by clinical stage. Clinical stage is documented for 86% of the total cohort (n=1,858). Clinical stage is unknown for n=301, (14%) of the cohort. See Appendix C for clinical stage definition

Figure 3: ***Total cohort distribution of sex by clinical stage at diagnosis in 2021.***

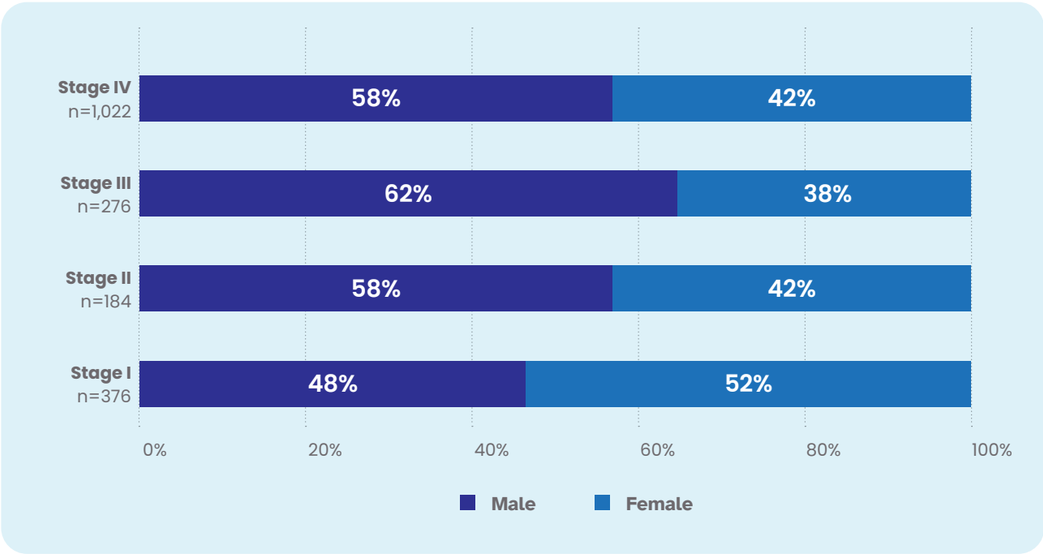


Figure 4: ***Total cohort distribution of age by clinical stage at diagnosis in 2021.***

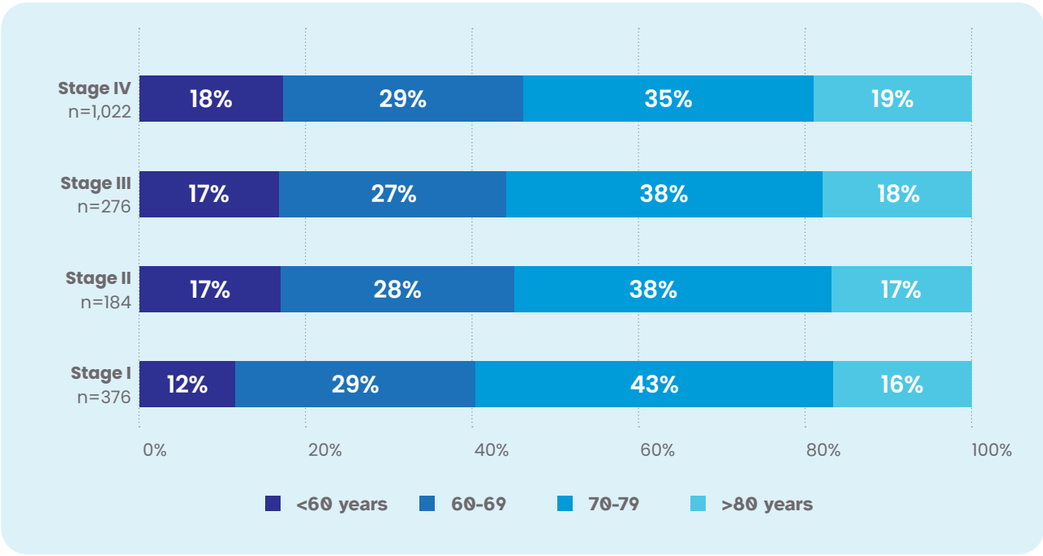
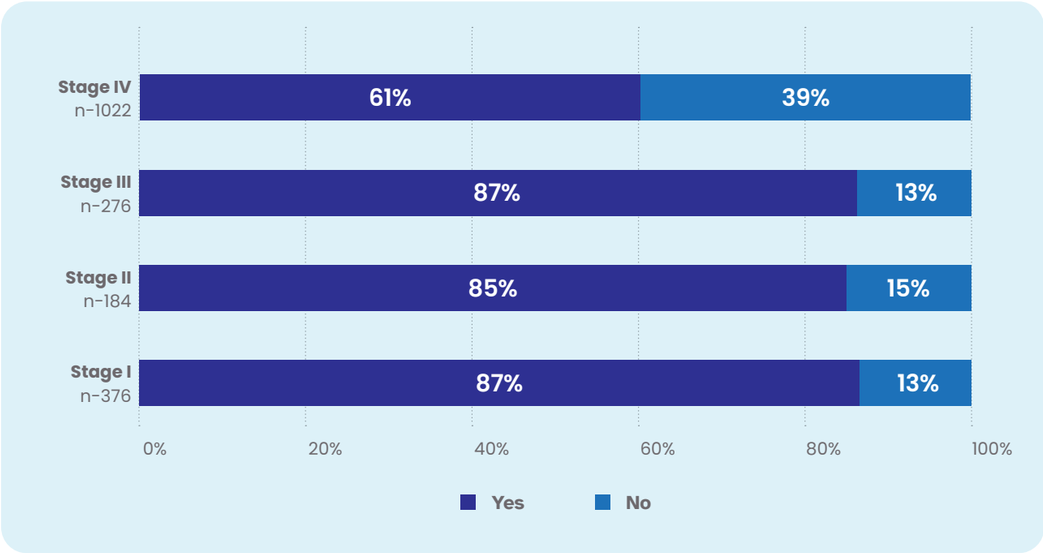


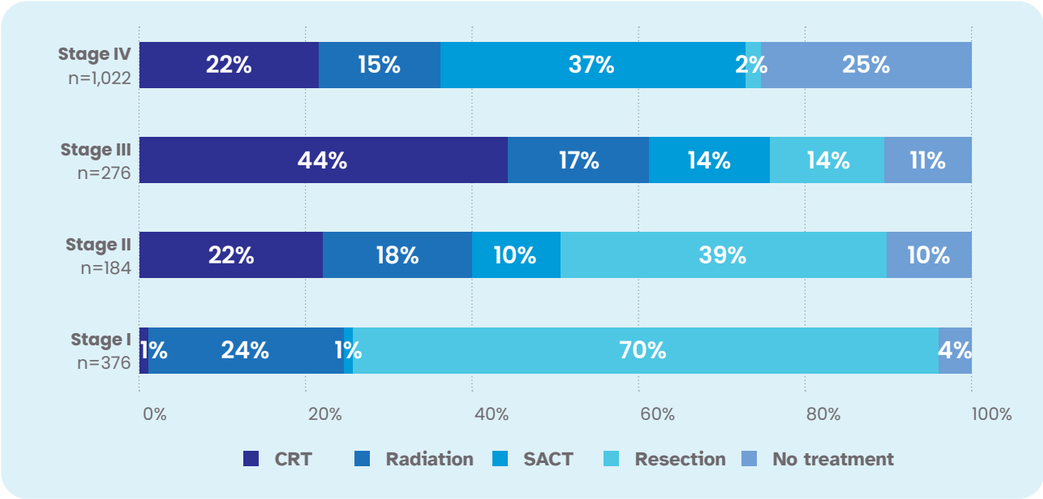
Figure 5: ***Total cohort distribution of MDM presentation by clinical stage at diagnosis in 2021.***



2021 Treatment By Clinical Stage

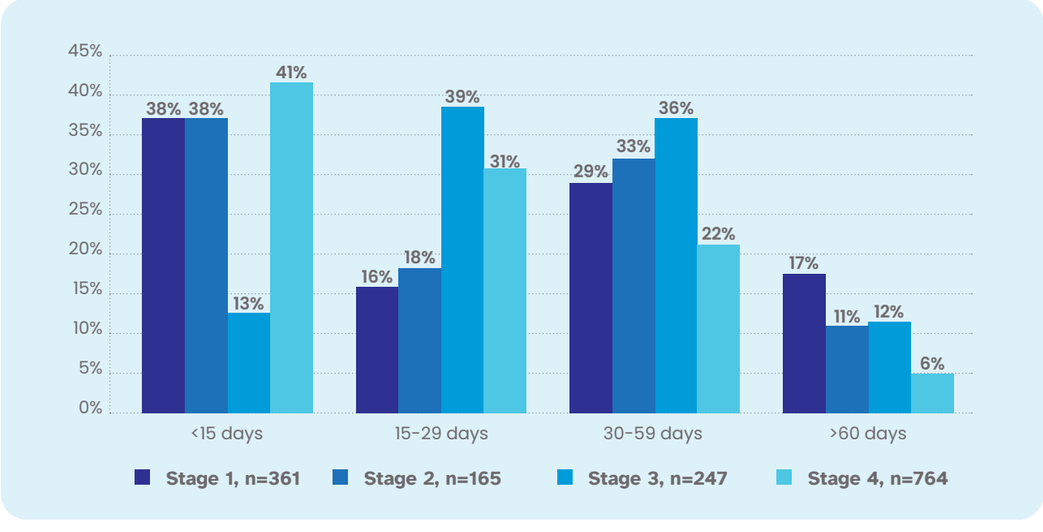
Figure 6 records the first treatment type documented. First treatment includes CRT alone (chemo-radiation), Surgical Resection, Radiation or Systemic Anti-Cancer Treatment (see Appendix B and C for definitions). Clinical stage is unknown for n=301, (14%) of the cohort.Figure 6 records the first treatment type documented. First treatment includes CRT alone, Surgical Resection, Radiation or Systemic Anti-Cancer Treatment. Clinical stage is unknown for n=301, (14%) of the cohort.

Figure 6: ***Total cohort distribution of first treatment by clinical stage at diagnosis in 2021.***



This graph records the first treatment type received and documented. For patients diagnosed with a primary lung cancer in 2021 who have documented clinical stage at diagnosis, (n= 1,858), 96% of patients with Stage 1 receive treatment, compared to 75% of those with Stage IV at diagnosis.

Figure 7: ***Total cohort distribution of time from diagnosis to first treatment, by clinical stage in 2021.***



NOTE: Includes patients who receive treatment, have documented clinical stage at diagnosis and a date for first treatment received, n=1,539 (87%).

Clinical Quality Indicators For 2021

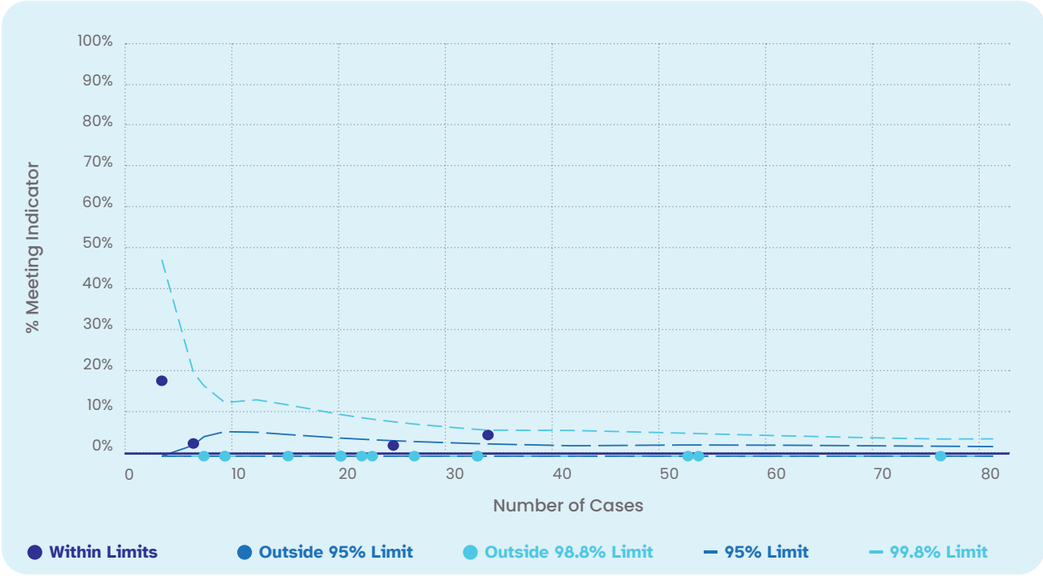
The VLCR collects and reports on data relating to 24 clinical quality indicators (QIs).

The VLCR clinical quality indicators have been developed by an expert working group. They are risk- adjusted and benchmarked against the VLCR 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. Appendix B, C lists all QIs with definitions. More detail of longitudinal change in QIs can be accessed via the VLCR website www.vlcr.org.au "Summary Document 2012-2020".

The following quality indicators are grouped to reflect six specific domains to improve core quality of health by delivering health care that is: **safe, effective, patient-centred, timely, efficient and equitable** [1].

Safe Health Care

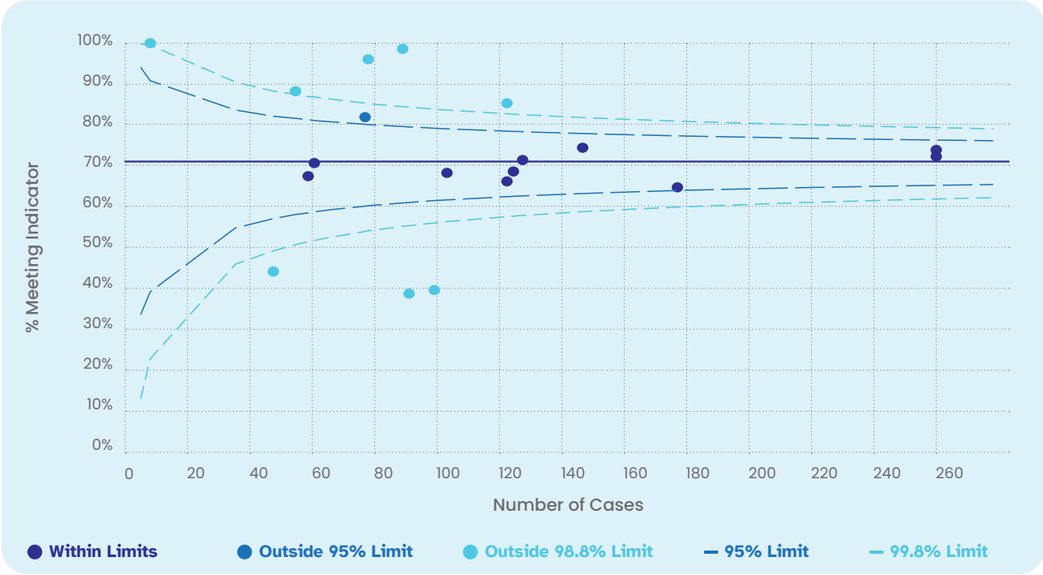
Figure 8: ***Proportion of patients with NSCLC who died within 30 days of lung resection (QI 15) in 2021.***



Total cohort mean 1%

Effective Health Care

Figure 9: ***Proportion of patients presented to a lung MDM (QI 9) in 2021***

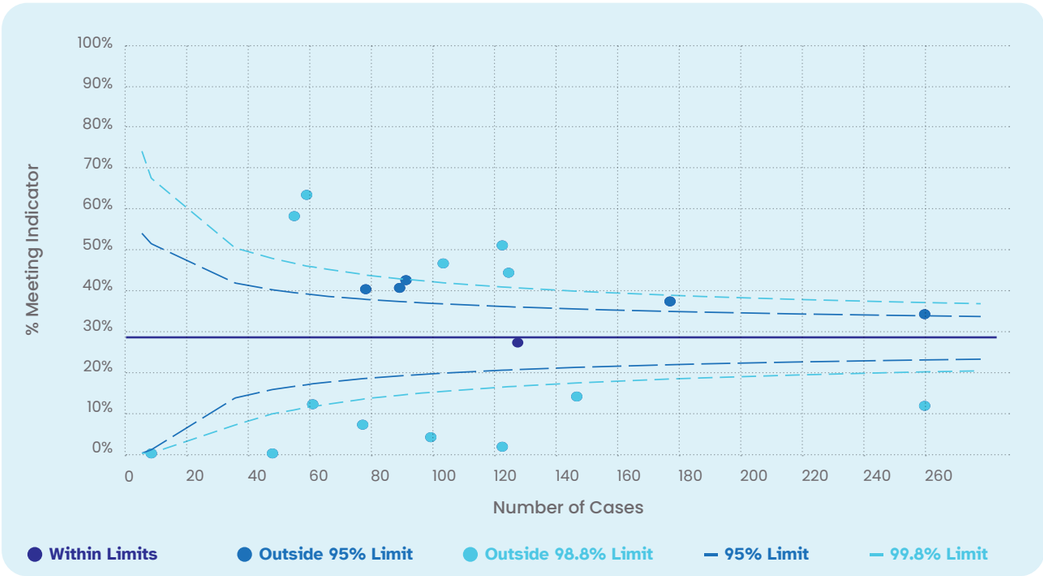


NOTE: N = 2,116 Risk adjusted for patient age, sex and clinical stage.

Total cohort mean 72%

Patient-Centred Health Care

Figure 10: ***Proportion of patients with documented screening for supportive care (QI 5) in 2021.***

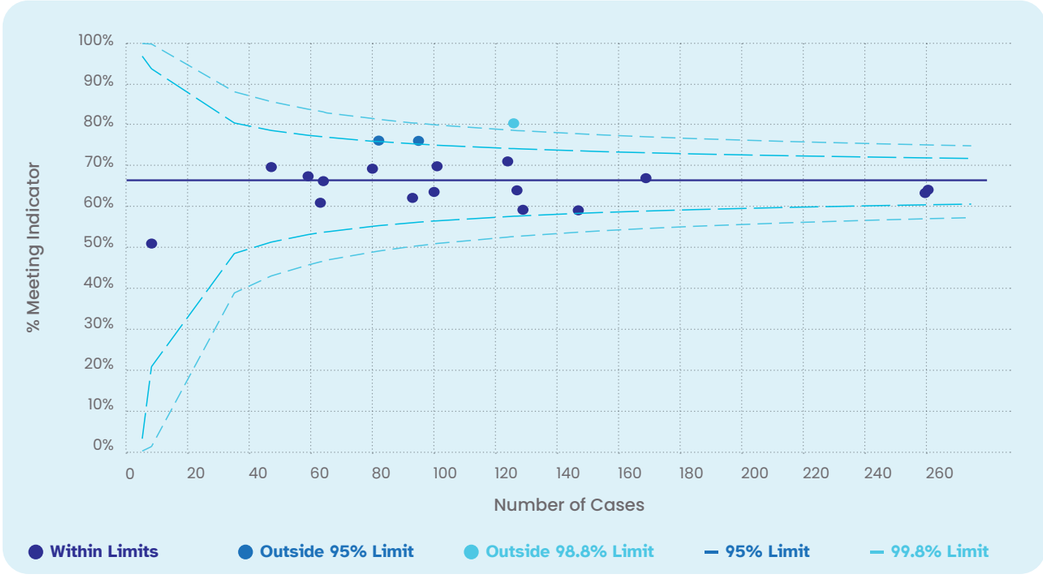


NOTE: N = 2,159 Risk adjusted for patient age, sex and clinical stage.

Total cohort mean 29%

Timely Health Care

Figure 11: ***Proportion of patients where referral to diagnosis date within 28 days (QI 1) in 2021.***

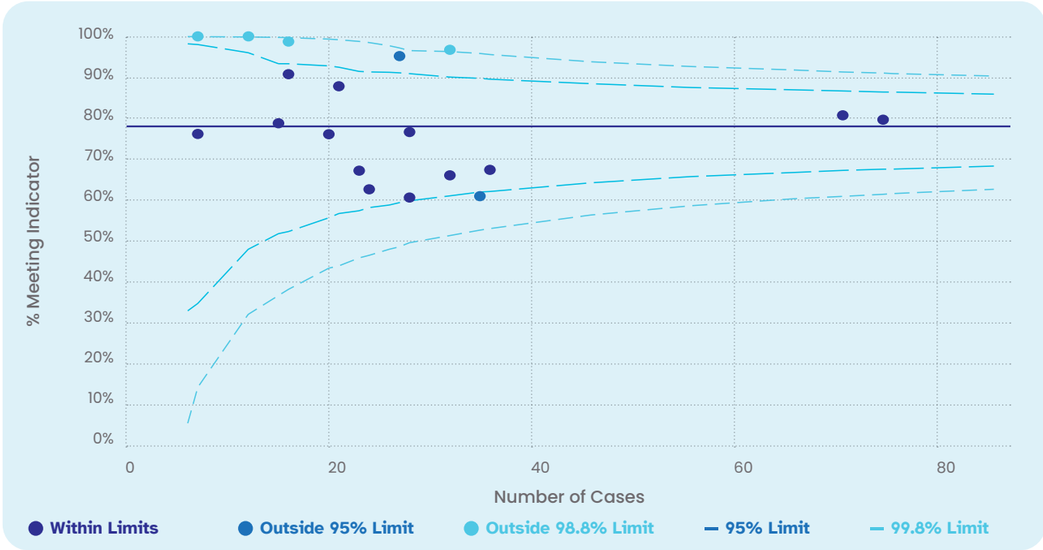


NOTE: N = 2,116 Risk adjusted for patient age, sex and clinical stage.

Total cohort mean 68%

Efficient Health Care

Figure 12: ***Proportion of patients with NSCLC (clinical stage IIIB, IIIC and IV) who have ECOG (0-1) who have commenced chemotherapy (QI 18) in 2021***



NOTE: N = 525 Risk adjusted for patient age, sex and clinical stage.

Total cohort mean 78%

Equitable Health Care

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 [2]. The lowest deciles indicate greater disadvantage [1-20%] and the higher deciles indicate lack of disadvantage [81-100%].

Figure 13: ***NSCLC referral to diagnosis interval by health service in 2021.***

Figure 14: ***NSCLC, referral to diagnosis interval by IRSAD in 2021.***

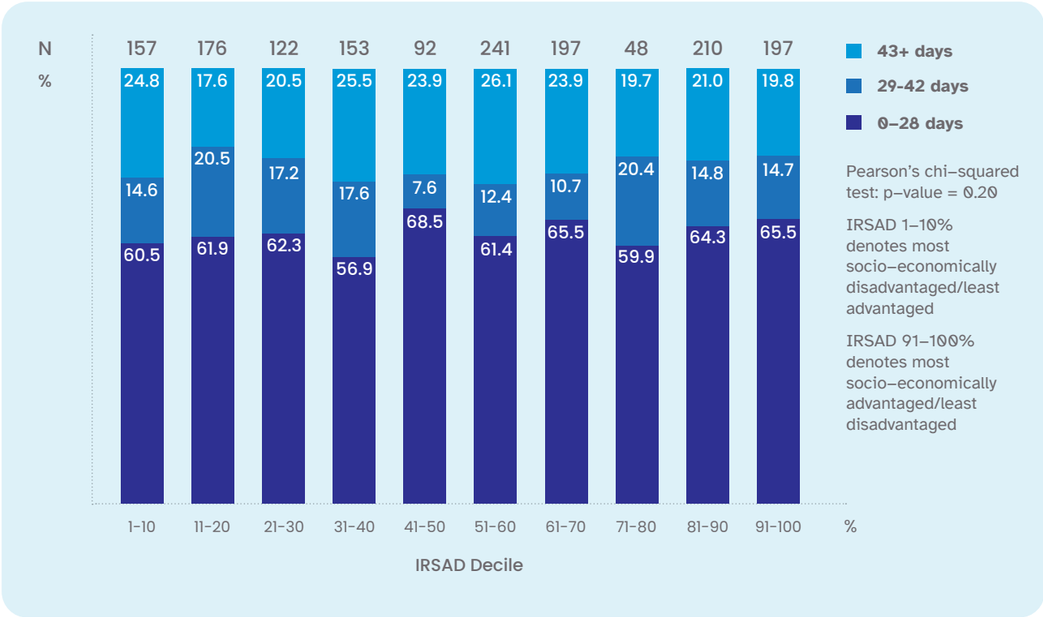


Figure 15: ***NSCLC (non-squamous) Stage IV with EGFR test by IRSAD in 2021***

Patient Registrations In The VLCR Overtime

There are 15,261 newly diagnosed patients with lung cancer within the VLCR database as of December 2021.

Figure 16: ***Total cohort patient registrations, overtime 2011 to 2021.***

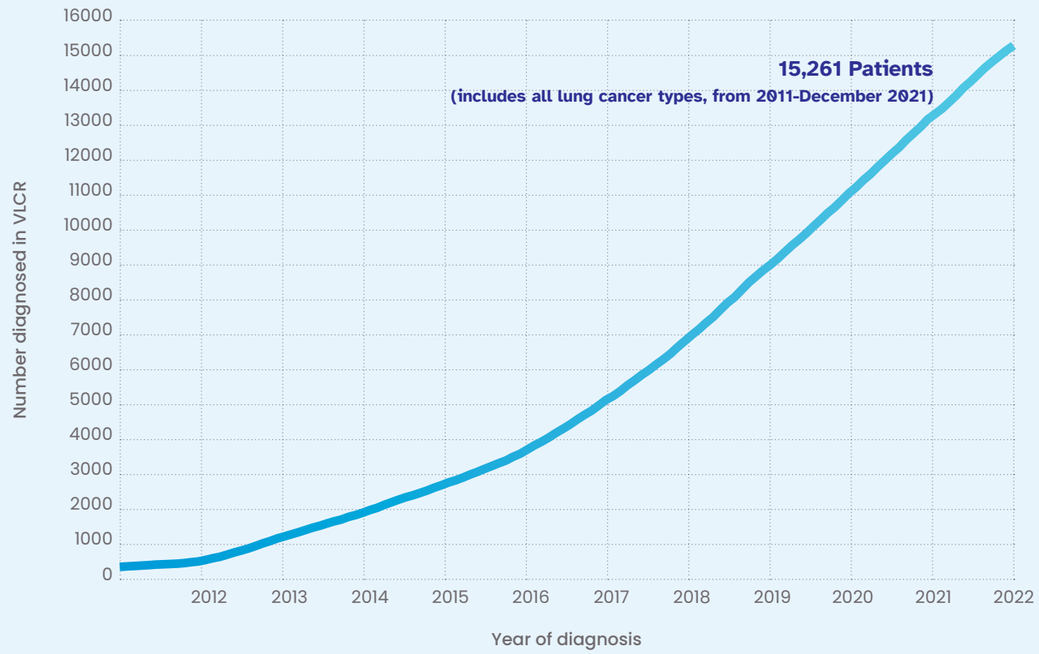


Figure 17A: ***Total cohort (n=15,261) by lung cancer type***

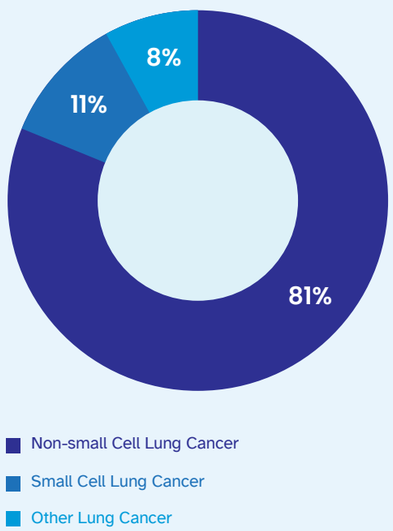
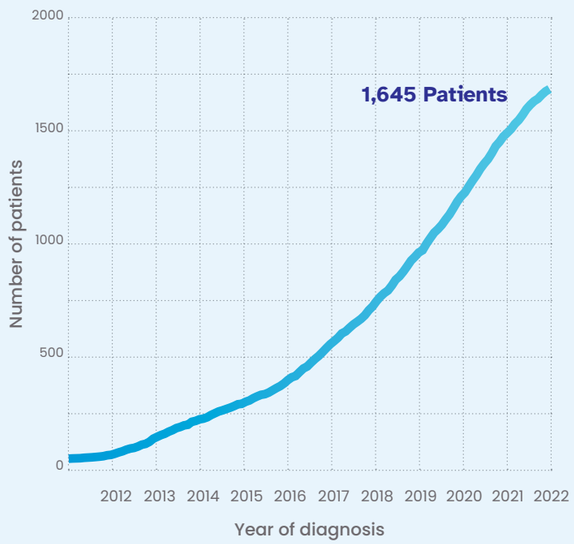


Figure 17B: ***Total SCLC patient registrations from 2011- 2021***



Survival Analysis 2011-2021 NSCLC Cohort

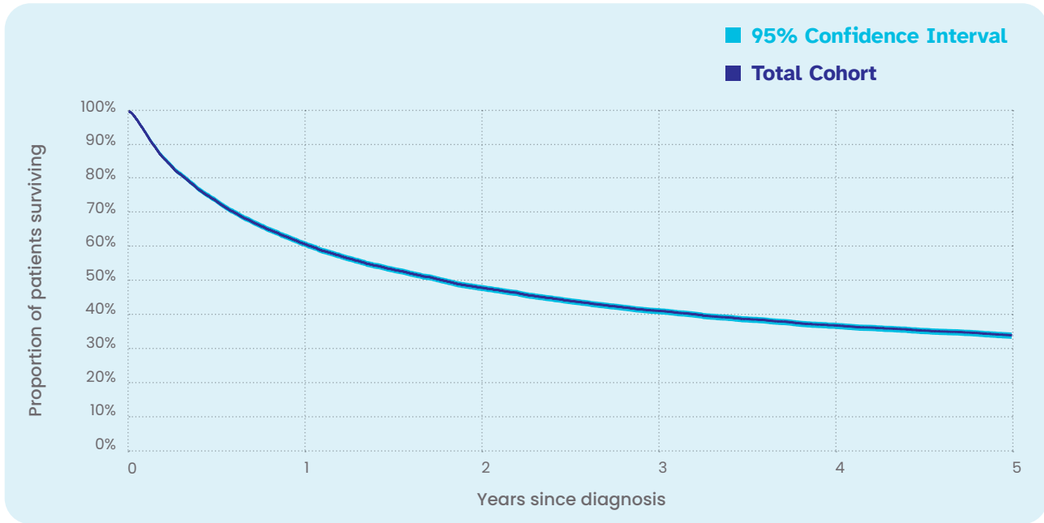
Kaplan-Meier estimates of survival using 2011-2021 VLCR registrations are presented in Figure 18-21 for patients diagnosed with NSCLC (n=12,332). Survival is also stratified by sex, age quartile groups and clinical stage in Figures 8-10. Survival rates are presented at annual time intervals from date 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 19th, 2023. 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 is used to further populate the death date field.

Figure 18: ***NSCLC overall survival (n=12,332), 2011 to 2021.***

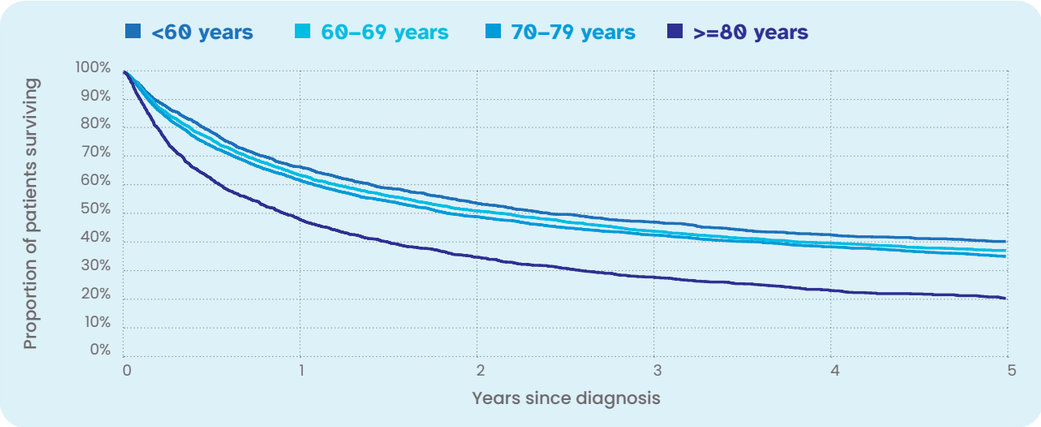


Number at risk	0	1	2	3	4	5
	12,332	7,458	5,112	3,632	2,494	1,658

5-Year Survival **NSCLC** = 32%

There is approximately a 14% difference between 1-year survival estimates for NSCLC patients aged 70 to 79 years compared to 80 years or older.

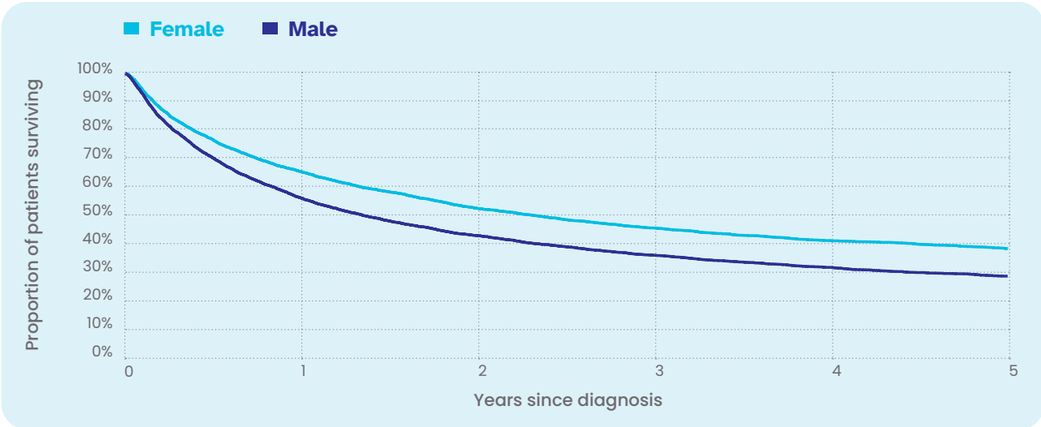
Figure 19: ***NSCLC survival by age, 2011 to 2021.***



Number at risk	0	1	2	3	4	5
<60 years	2,152	1,426	1,017	735	513	357
60-69 years	3,660	2,319	1,628	1,160	793	514
70-79 years	4,389	2,699	1,831	1,322	929	626
>=80 years	2,131	1,014	636	415	259	161

1-Year Survival	70-79 = 37%	>=80 = 22%

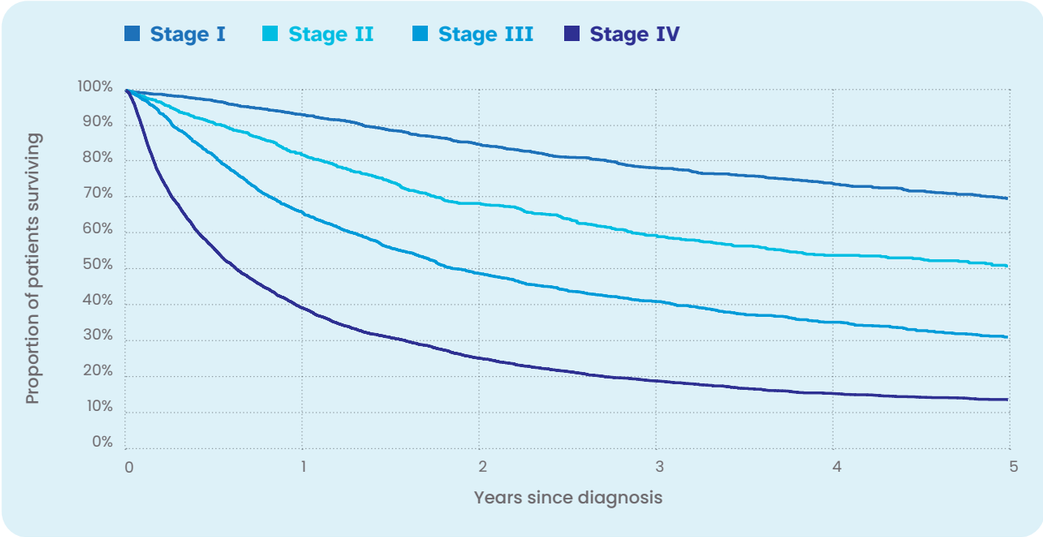
Figure 20: ***NSCLC survival by sex, 2011 to 2021.***



Number at risk	0	1	2	3	4	5
Female	5,433	3,565	2,486	1,784	1,237	831
Male	6,899	3,893	2,626	1,848	1,257	827

5-Year Survival	Female = 39%	Male = 29%

Figure 21: ***NSCLC survival by clinical stage, 2011 to 2021.***



Number at risk	0	1	2	3	4	5
Stage I	1,986	1,851	1,433	1,086	778	520
Stage II	1,050	861	639	468	329	226
Stage III	1,985	1,311	865	604	391	258
Stage IV	5,206	2,051	1,144	675	395	250

Small Cell Lung Cancer (SCLC)

In 2021, approximately 10% of the VLCR cohort were diagnosed with SCLC (n=211).

Of this cohort, 197 (93%) had clinical stage at diagnosis: Limited stage, n=47 and Extensive stage, n= 150. The following graphs are provided to show demographics, equity of access to care, treatment [Lung Cancer Resection, Radiation or Systemic Anti-Cancer Treatment] and survival for this group of patients.

A retrospective cross-sectional study utilising prospectively collected data from the Victorian Lung Cancer Registry (VLCR) from 2011-2019 has been published in 2022, with results showing active treatment rates in Victoria are high, survival outcomes are comparable to international reports and MDM presentation + receipt of multimodality treatment is associated with improved survival [3].

2021 SCLC Characteristics by Clinical Stage

Figure 22: ***SCLC distribution of sex by clinical stage at diagnosis in 2021.***

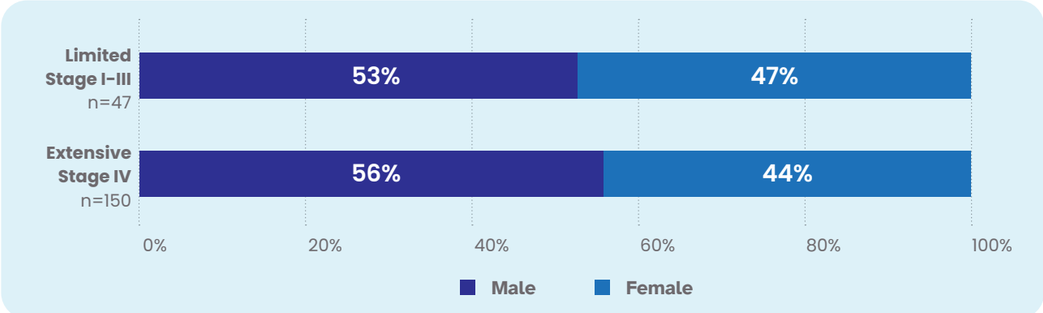
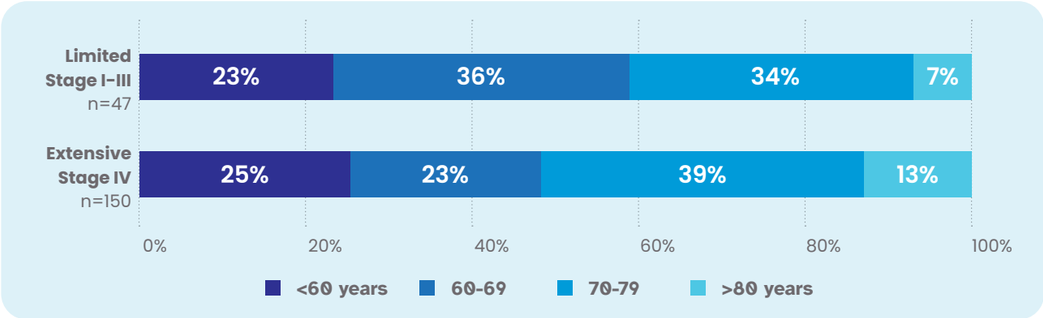


Figure 23: ***SCLC distribution of age by clinical stage at diagnosis in 2021.***



In 2021, 54% of people diagnosed with SCLC with clinical stage documented at diagnosis identified as male and 46% as female. The most common age category for patients diagnosed with limited stage is 60-69 years of age and for patients with extensive stage, it is 70-79 years of age.

2021 SCLC Treatment by Clinical Stage

Treatment includes CRT (chemo-radiation), Lung Resection, Radiation or Systemic Anti-Cancer Treatment (see Appendix B and D for definitions). The following graphs record the first documented treatment type.

Figure 24: ***SCLC distribution of patients presented to MDM by clinical stage at diagnosis in 2021.***

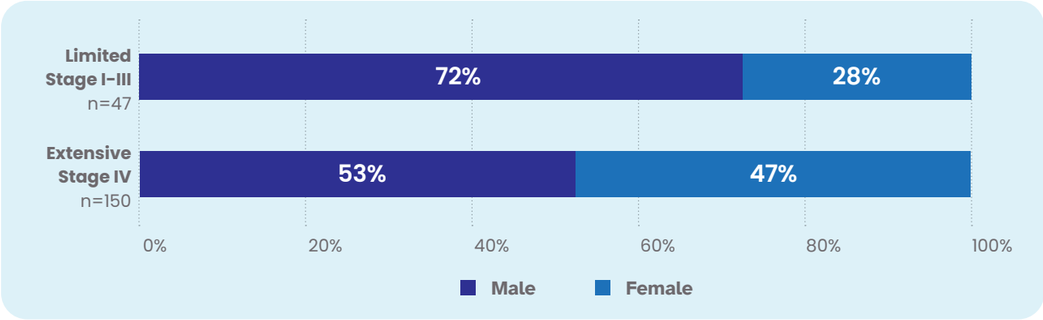
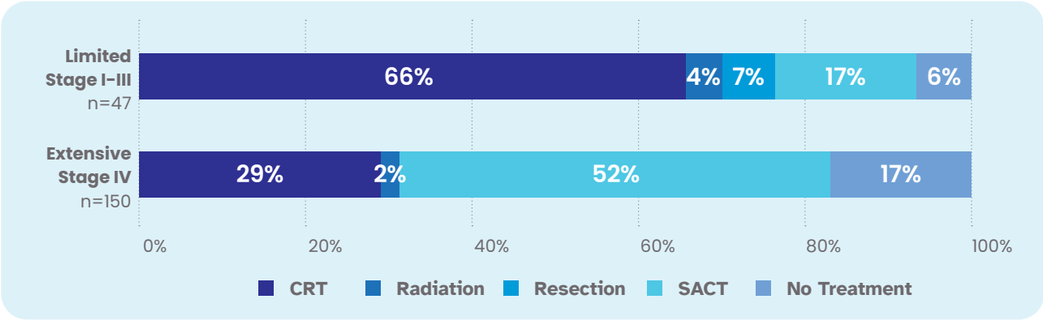
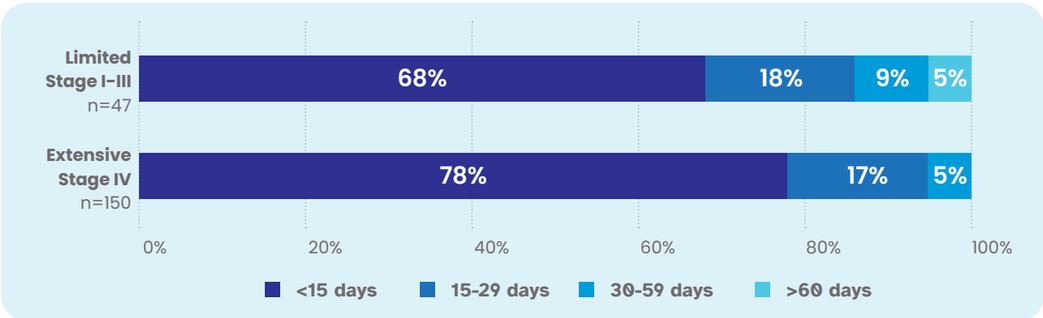


Figure 25: ***SCLC distribution of first treatment (by treatment type) and clinical stage at diagnosis in 2021.***



For patients diagnosed with SCLC in 2021 who have documented clinical stage at diagnosis, (n= 197) treatment is received for Limited Stage (94%) and Extensive Stage (83%).

Figure 26: ***SCLC time from diagnosis to first treatment, by clinical stage in 2021.***



The majority of patients diagnosed with SCLC with clinical stage recorded at diagnosis received their treatment within 15 days of diagnosis (Limited, 68%) and (Extensive, 78%).

SCLC 2021 Equitable Care

Figure 27: *SCLC referral to diagnosis interval by IRSAD in 2021.*

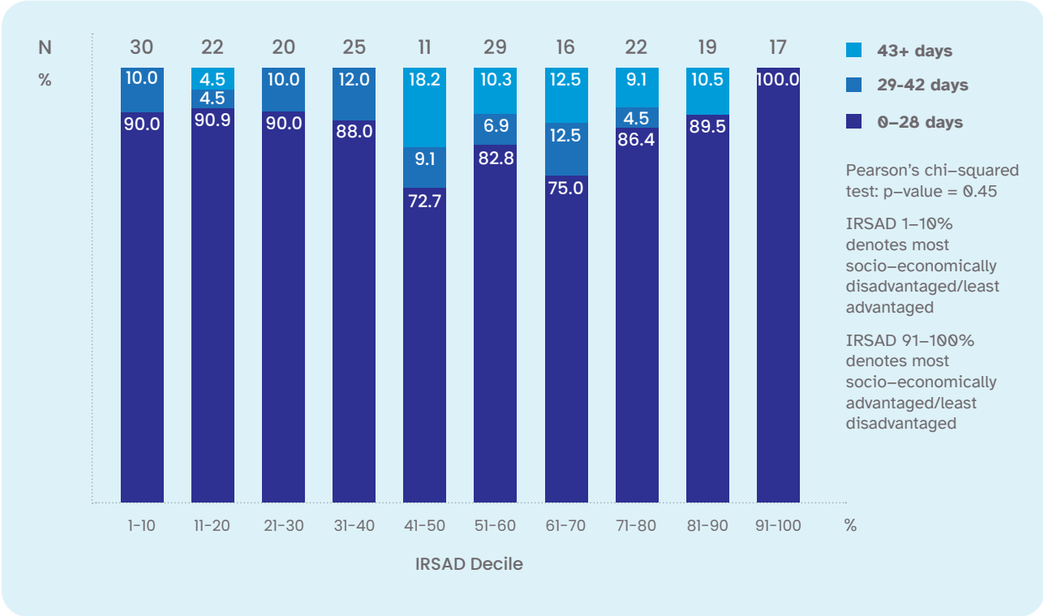
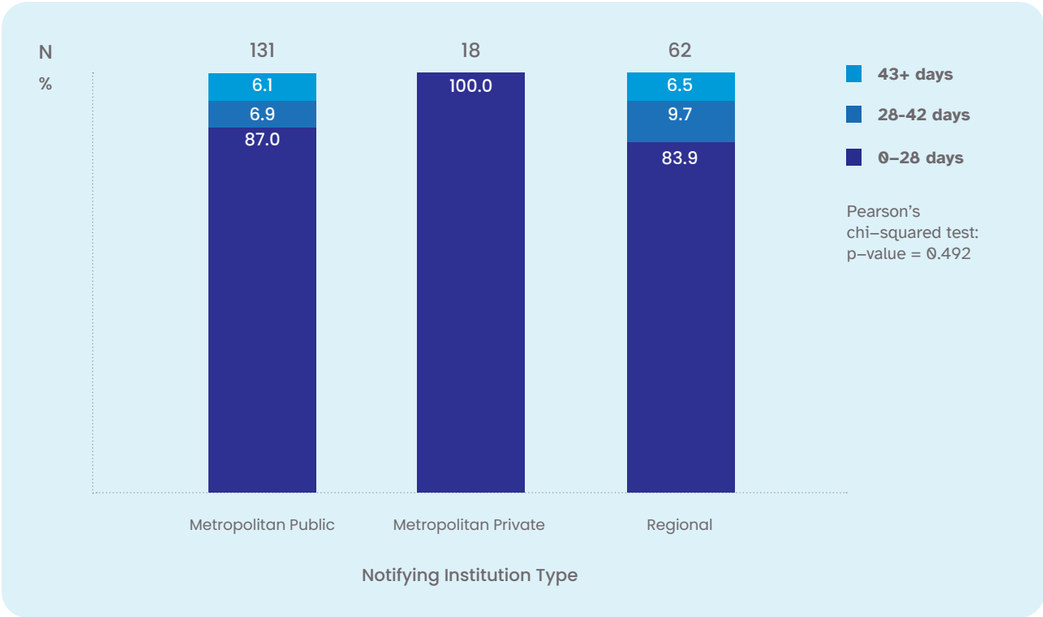


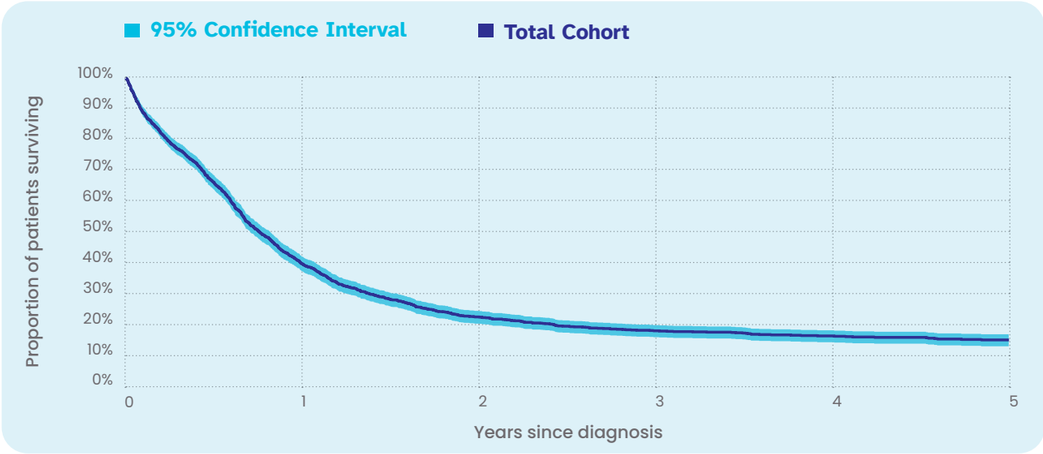
Figure 28: *SCLC referral to diagnosis interval by health service in 2021.*



Survival Curves for SCLC

The following survival figures represent the total cohort of patients diagnosed with SCLC from 2011-2021 in the VLCR (n=1,645). The analysis includes survival by total cohort (n=1,645) and by clinical stage at diagnosis (n=1,514).

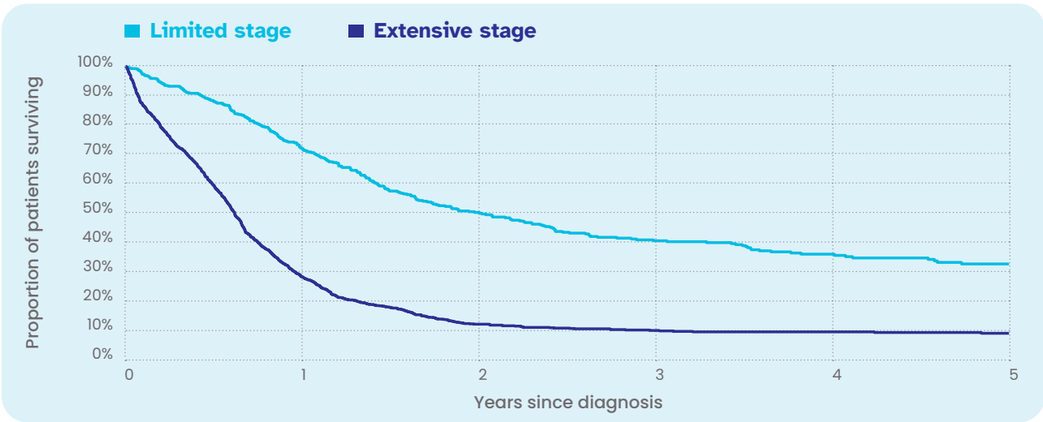
Figure 29: *SCLC overall survival, 2011 to 2021.*



Survival Rates* **1 Year** = 40.1% **2 Years** = 22.9% **5 Years** = 15.5%

*Survival rates were derived using the Kaplan-Meier survival function.

Figure 30: *SCLC survival by clinical stage, 2011 to 2021.*



Number at risk	0	1	2	3	4	5
Limited stage	415	299	195	133	86	58
Extensive stage	1,099	311	114	66	46	32

Total Cohort Longitudinal Outcomes 2012-2021

The VLCR has been collecting data since 2011. A number of analyses have been undertaken to monitor change in practice, including MDM presentation. The following analyses includes data that shows the steady and statistically significant improvement in MDM presentations from 2016 to 2021 and the decrease in the number of patients having a resection for lung cancer within 14 days of diagnosis.

Figure 31: ***Proportion of patients being presented to an MDM overtime, 2012-2021.***

Trend plot for: CQI–9: Proportion of patients with presentation at a lung cancer multidisciplinary meeting (MDM) documented. (n = 15,716).

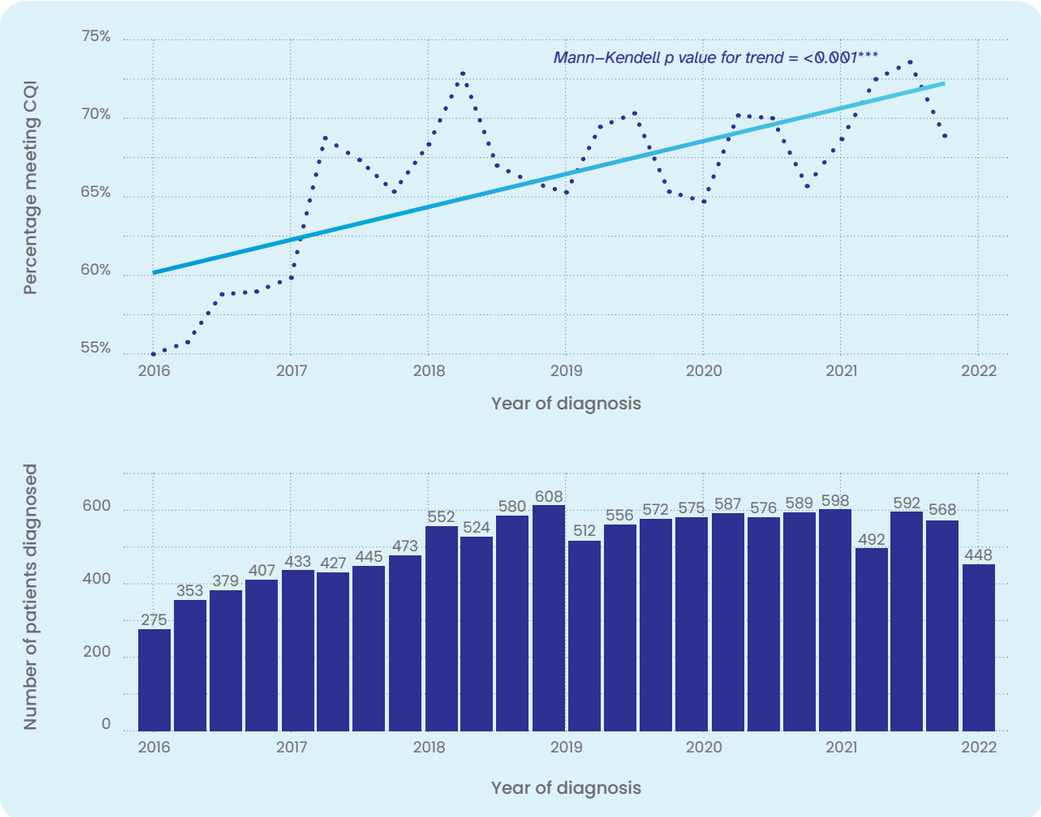


Figure 32: ***Proportion of patients with NSCLC, where time from diagnosis to surgical resection was <= 14days, overtime 2012-2021.***

Trend plot for: CQI–3: Proportion of patients with NSCLC where time from diagnosis to surgery* = 14 days (n = 3,526).

Appendices

Appendix A: *List of Figures*

Appendix B: *Glossary of Terms, Acronyms*

ACSQHC	Australian Commission for Safety and Quality in Healthcare
AIHW	Australian Institute of Health and Welfare
ATSI	Aboriginal and Torres Strait Islander people
CRT	Chemo-radiation therapy, with the start date of chemotherapy and radiation treatment within 90 days of each treatment start date
CTNM	Clinical stage of a primary tumour, defined by Tumour, Node, Metastasis
HIS	Hospital Information Systems
IASCLC	International Association for the study of Lung Cancer
ICD-10-AM	The International Statistical Classification of Diseases and Related Health Problems, Tenth Revision, Australian Modification
IRSAD	The Index of Relative Socio-economic Advantage and Disadvantage (IRSAD) summarises information about the economic and social conditions of people and households within an area, including both relative advantage and disadvantage measures. Decile 1 [0-10%] (most disadvantaged) - Decile 10 [91-100%] (most advantaged)
NSCLC	Non-small cell lung cancer
PET	Positron emission tomography scan
PTN	Pathological stage of primary tumour
QI	Quality Indicator
SCLC	Small cell lung cancer
SEIFA	Socio-Economic Index for Australia
SACT	Systemic anti-cancer treatment includes any chemotherapy, immunotherapy or targeted therapy.
VATS	Video-assisted thoracoscopic surgery
VIC-BDM	Victorian Registry of Births, Deaths and Marriages
VLCR	Victorian Lung Cancer Registry

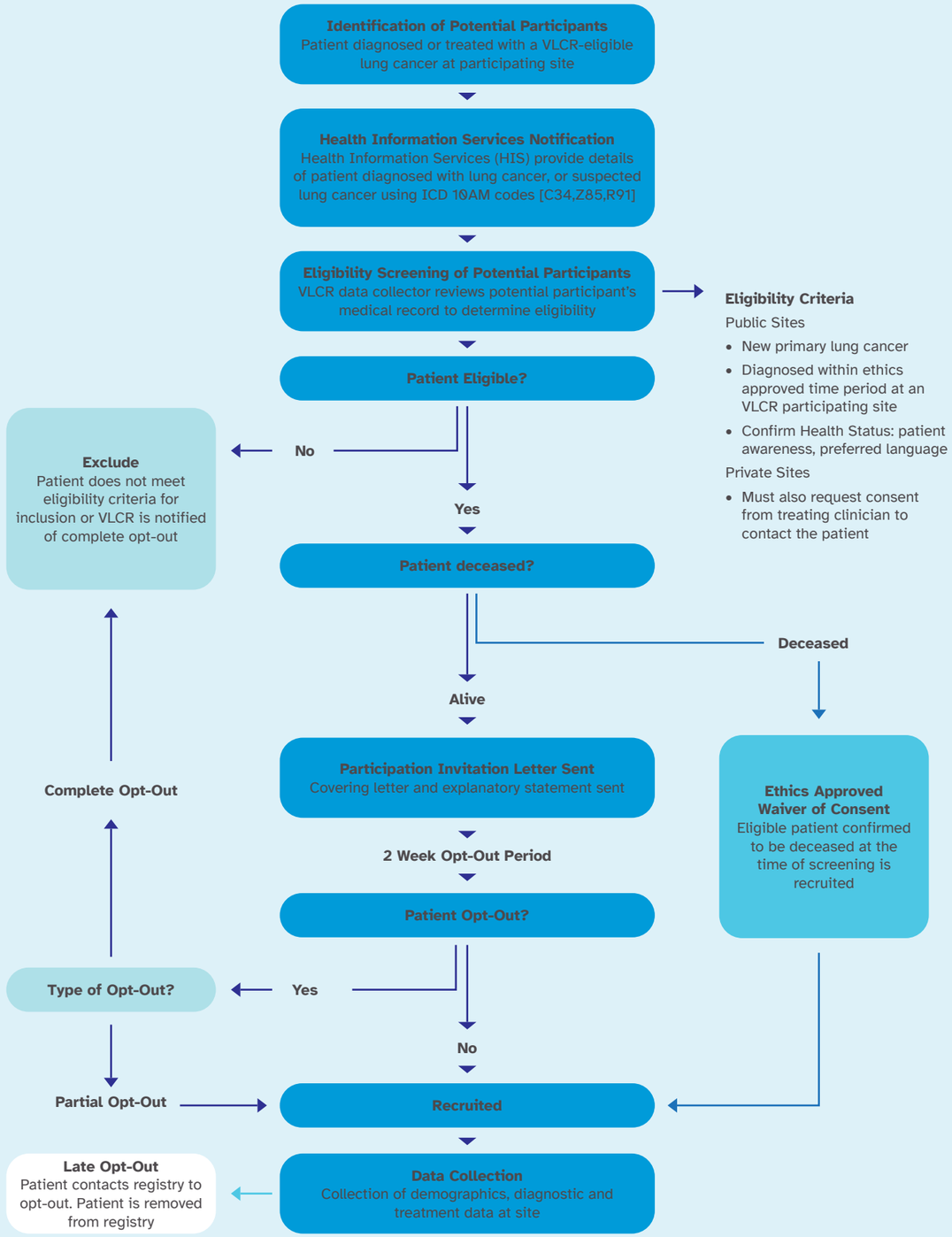
Appendix C: *VLCR data variable definitions*

VLCR Data Item	*Definition*
Clinical Staging (cTNM)	Staging is recorded using the International Association for the Study of Lung Cancer (8th edition), 2015. If cTNM are not documented, the patient clinical stage will be "cannot be assessed". If cTNM are not stated, but medical records state "metastatic cancer", stage IV is entered. If patients do not have clinical staging available in the medical records, quality indicators and risk-adjustment calculations that use clinical stage may be impacted. In this report for Figures 3-5, SCLC limited stage is defined as Stage I-III, and SCLC Extensive stage is defined as stage IV.
cTN agrees with pTN	Clinical staging is the first staging documented at diagnosis. Pathological staging is staging documented following resection. The staging concordance definition uses the Danish Lung Cancer Registry (DLCR) staging concordance definitions. Concordance rules In the indicator this include all patients with valid TNM registrations (no Tx, Nx unless M=1, and no Mx), and the population includes patients with a surgical resection. There is concordance if 1. cTNM is Tx, T0, T1a, T1b, T1c, T2a, T2b or T3 & pTNM is not T4 2. cTNM is Nx, N0, N1 and pTNM is not N2 or N3 3. cTNM is N2 and pTNM is not N3 4. cTNM is M0 and pTNM is not M1a, M1b, M1c
Date of diagnosis	The date of diagnosis is the date a pathological test confirms a primary lung cancer. If a patient does not have a pathological test to confirm a primary lung cancer, the date of diagnosis is the date a clinical test has confirmed a primary lung cancer, supported by medical correspondence/ MDM reports confirming a primary lung cancer .
Death date	Death dates are sourced from Victorian – Births, Deaths and Marriages (Vic-BDM), or from site medical records, or from administrative data (HIS reports). If Vic-BDM state a "partial match" that is not verified by site medical records, public death notices are used to verify the death date.
ECOG (performance status)	Eastern Cooperative Oncology Group Performance Status Scale. If patients do not have ECOG documented in medical records, indicators using ECOG may be impacted.
EGFR ALK ROS1 ADL1	A patient is recorded as tested for molecular profiling if there is evidence found in pathology reports, MDM notes or medical correspondence that the test has been completed. Molecular profiling test results are collected by VLCR collectors, but not included in this report.
First treatment (any intent)	Any documented resection, radiotherapy, chemotherapy or targeted immunotherapy for primary lung cancer.
Lung Cancer Type	Lung cancer type is derived from reported Morphology. If patients do not a lung cancer type available, indicators that specify a lung cancer type may be underreported.
Multidisciplinary meeting (MDM)	Refers to a Lung-MDM. This indicator includes any Lung-MDM presentation before or after diagnosis and treatment. The MDM date recorded is the last MDM before treatment is commenced.
NSCLC Non-squamous	Includes patients with documented morphology mapped to NSCLC. Excludes morphology for NSCLC squamous cell [M8046, 8050-53, 8070-73,8083-4]
Pathological diagnosis	Diagnosis confirmed by cytological or histological findings
Pathological Staging (pTNM)	Staging is recorded using the International Association for the Study of Lung Cancer (8th edition), 2015. If pTN are not documented, the patient pathological stage will be "cannot be assessed. If pathological staging is not documented, indicators using pathological stage may be impacted.
Platinum chemotherapy following resection	Platinum chemotherapy (Carboplatin or Cisplatin) given within 90 days following resection.
Referral	Correspondence from a primary care provider (usually GP) or specialist requesting further investigation of suspected lung cancer.
Referral to Palliative care	This is referral to any palliative care team/s found in the medical records, including referral to a palliative care clinician, community nurse, or to a palliative care service or facility.
Supportive Care Screening Tool (SCST)	This includes documentation in the medical records of the SCST developed by Southern Melbourne Integrated Cancer Service (SMICS) to measure patient distress, the National Comprehensive Cancer Network (NCCN) Distress thermometer or an equivalent measure of patient distress screening completed and notified to the VLCR.
Surgical lung cancer resection	Includes pneumonectomy, lobectomy, segmentectomy or wedge resection. If the only resection performed is a wedge resection and cTNM [IIIBC-IV], or if cTNM "cannot be assessed" and pTNM is IIIBC-IV, assume this is a diagnostic procedure and not a lung resection. Resection with neo-adjuvant treatment is reported as resection in Figure 6.
Systemic anti-cancer treatment (SACT)	SACT includes any chemotherapy, immunotherapy or targeted therapy.

Appendix D: *VLCR 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 any intent 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 dates available.
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 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
Tissue Diagnosis Indicator		
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
12	Number of patients with confirmed tissue diagnosis (malignant cytology or histology)	Number of patients in Registry
Treatment Indicators		
13	Number of patients with NSCLC (clinical stage I, II) who have had surgical resection	Number of patients with NSCLC
14	Number of patients with NSCLC (clinical stage I or II) and resection with ≥ 5 lymph nodes dissected	Number of patients with NSCLC (clinical stage I or II) who have undergone surgical resection
15	Number of patients with NSCLC who have had a surgical resection and died within 30 days of surgery.	Number of patients with NSCLC who have undergone surgical resection
16	Number of patients with NSCLC who have had a surgical resection and died within 90 days of surgery.	Number of patients with NSCLC who have undergone surgical resection
17	Number of patients receiving anti-cancer treatment (surgery, radiotherapy, chemotherapy, immunotherapy or targeted therapy)	Total number of patients in Registry
18	Number of patients with NSCLC (stage IIIB, IIIC or IV) who have ECOG (0-1) and have commenced chemotherapy, immunotherapy or targeted therapy	Number of patients with NSCLC (stage IIIB, IIIC, IV) + ECOG (0-1)
19	Number of patients with NSCLC (pathological stage II, III) receiving platinum chemotherapy after resection	Number of patients with NSCLC (pathological stage II, III) who have undergone a surgical resection
20	Number of patients with lung cancer where time from the start date of chemotherapy, immunotherapy or targeted therapy to death date is ≤30 days.	Number of patients receiving chemotherapy, immunotherapy or targeted therapy with treatment dates available
Palliative care Indicator		
21	Number of patients with NSCLC (stage IV) referred to palliative care ≤ 8 weeks of diagnosis	Number of patients with NSCLC (stage IV)
Molecular profiling		
22	Number of patients tested for EGFR	Number of patients with NSCLC (non-squamous) Stage IV
23	Number of patients tested for ALK	Number of patients with NSCLC (non-squamous) Stage IV
24	Number of patients tested for ROS1	Number of patients with NSCLC (non-squamous) Stage IV
25	Number of patients tested for ADL1 expression	Number of patients with NSCLC Stage IV

Appendix E: *Participant Recruitment and Data Transfer in the VLCR*



Appendix F: *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 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 G: *VLCR Steering Committee Membership in 2021*

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.
Mr Tom Wood	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.
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.
Dr Susan Harden	VLCR Senior Research Fellow, Radiation Oncologist, Peter MacCallum Cancer Centre
Dr Marliese Alexander	Pharmacist, Peter MacCallum Cancer Centre
Associate Professor Tom John	Medical Oncologist, Peter MacCallum Cancer Centre
Dr Simon Knight	Cardiothoracic Surgeon, Austin Hospital

Appendix H: *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-AM 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 I: *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, and other public death notices. Deaths that occur interstate or overseas may not be captured.

Appendix J: *Publications in 2021 / 2022*

Impacts of lung cancer multidisciplinary meeting presentation: Drivers and outcomes from a population registry retrospective cohort study. Lin T, Pham J, Paul E, Conron M, Wright G, Ball D, Mitchell P, Atkin N, Brand M, Zalcberg J, Stirling RG.Lung Cancer. 2022 Jan;163:69-76

Variations in lung cancer care and outcomes: How best to identify and improve standards of care? Brims F, Leong T, Stone E, Harden S, Marshall H, Navani N, Stirling R.Respirology. 2021 Dec;26(12):1103-1105

Victorian Lung Cancer Service Redesign Project: impacts of a quality improvement collaborative on timeliness and management in lung cancer. Largey G, Briggs P, Davies H, Underhill C, Ross C, Harvey K, Blum R, Parker C, Guthrie C, Parente P, Trevorah B, Torres J, Mott C, Lancaster C, Brand M, Earnest A, Pellegrini B, Reed M, Zalcberg J, Stirling R.Intern Med J. 2021 Dec;51(12):2061-2068

Posttreatment Surveillance Challenges in the Era of Precision Medicine. Stirling RG.J Thorac Oncol. 2021 Oct;16(10):e77-e78. doi: 10.1016

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 Sep;51(9):1450-1456

Measurement properties of the 12-item Short Form Health Survey version 2 in Australians with lung cancer: a Rasch analysis. Soh SE, Morello R, Ayton D, Ahern S, Scarborough R, Zammit C, Brand M, Stirling RG, Zalcberg J.Health Qual Life Outcomes. 2021 May 31;19(1):157

Excess mortality and undertreatment in elderly lung cancer patients: treatment nihilism in the modern era? Pham J, Conron M, Wright G, Mitchell P, Ball D, Philip J, Brand M, Zalcberg J, Stirling RG.ERJ Open Res. 2021 May 24;7(2):00393-2020

Forecasting of Lung Cancer Incident Cases at the Small-Area Level in Victoria, Australia. Wah W, Stirling RG, Ahern S, Earnest A.Int J Environ Res Public Health. 2021 May 11;18(10):5069

Effect of Follow-Up Surveillance After Curative-Intent Treatment of NSCLC on Detection of New and Recurrent Disease, Retreatment, and Survival: A Systematic Review and Meta-Analysis. Stirling RG, Chau C, Shareh A, Zalcberg J, Fischer BM.J Thorac Oncol. 2021 May;16(5):784-797

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. 2021 Apr 15;148(8):1828-1838

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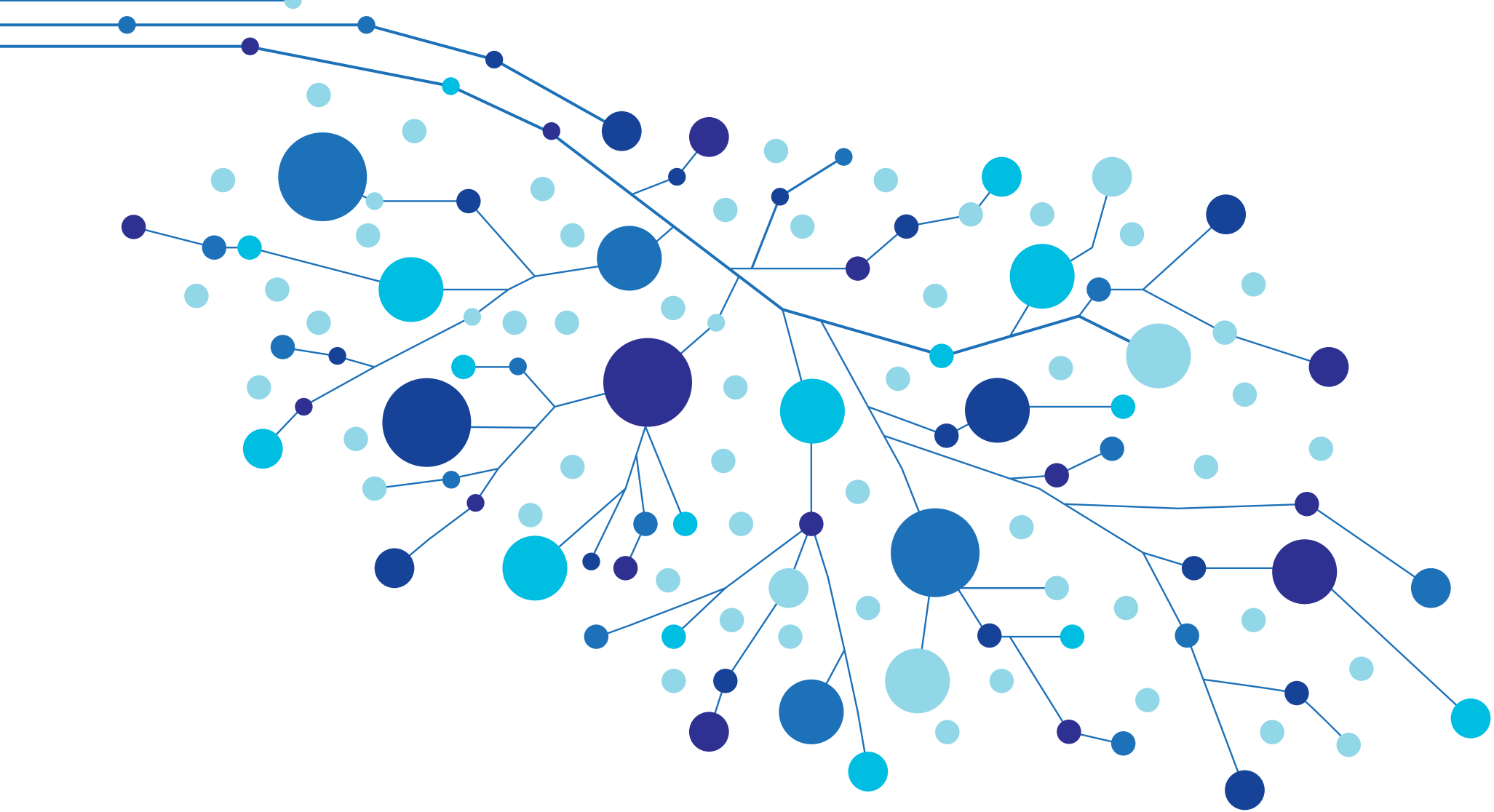
3. Joanna Huang , Wasek Faisal , Margaret Brand , Shantelle Smith , Marliese Alexander, Lisa Briggs, Matthew Conron, Mary Duffy , Thomas John , David Langton, Jacqueline Lesage , Michael MacManus , Paul Mitchell, Inger Olesen, Phillip Parente, Jennifer Philip , Evangeline Samuel, Javier Torres, Craig R Underhill, John R Zalcberg, Susan Harden, Rob Stirling. Patterns of care for people with small cell lung cancer in Victoria, 2011–19: a retrospective, population-based registry data study. Medical Journal of Australia, 2023



Annual Report 2021