Victorian Mesothelioma Outcomes Registry

Summary Report for 2022-2024 Cases

Foreword

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Mesothelioma is a rare cancer which most commonly arises in the pleural lining of the lungs and is almost always associated with a history of asbestos exposure. The Phase Three Asbestos National Strategic Plan 2024-2030 from the Australian Government Asbestos and Silica Safety and Eradication Council identifies 3 priorities for improving the lives of people with asbestos-related disease: earlier diagnosis, better access and ease of navigating care and support systems to appropriate treatment, and research to improve currently available diagnostic and therapeutic options[1]. Mesothelioma is the asbestos-related disease with the highest symptom burden and poorest prognosis, with the lowest 5-year survival out of all cancers in Victoria[2].

The Victorian Mesothelioma Outcomes Registry (VMOR), funded by Cancer Council Victoria, has collected detailed clinical and quality of life information on 301 participants diagnosed with mesothelioma between 2022-2024. This summary report highlights a number of areas where state support for people living with this asbestos cancer could be strengthened in line with the National Strategic Plan.

Regarding earlier diagnosis, our data identifies opportunities for improvement. Of our bespoke PROMs/PREMs survey[3,4] respondents, 58% reported experiencing symptoms for over two months before referral, and 28% had symptoms for over six months. From our key clinical quality indicators[5,6,7] referral to diagnosis occurred within 28 days for 62% of participants, though this varied from 52% to 76% across Victoria. Additionally, only 63% had documented asbestos exposure history in medical records, suggesting that systematic approaches to occupational history-taking could be developed.

Our data also highlights gaps in specialist services and access to support. Only 28% of participants had documented access to a specialist cancer nurse and supportive care screening, ranging from 25% to 35% across Victoria. Multidisciplinary meeting case discussions ranged from 54% to 81% across Victoria. These gaps carry a real human cost: 51% of patients reported significant fatigue, 46% reported weakness, and 40% reported their condition affected family life. Funding for a dedicated state-wide mesothelioma support nurse network could deliver equitable specialist nursing support, ensure timely contact with newly diagnosed patients, coordinate care navigation, connect patients with psychological and peer support services.

VMOR therapeutic data is both encouraging and troubling. People receiving first-line chemo/immunotherapy achieved a median survival of 14 months, compared 8.7 months median survival across all participants — a statistically significant benefit. Yet only 57% of participants received this, ranging from 38% to 66% across Victoria. This variation strongly suggests that access to evidence-based treatment is inequitable and potentially modifiable. We hope this report can lead to the establishment of a state-wide mesothelioma multidisciplinary team and research network to help standardise treatment and increase clinical trial access including targeted research into fatigue and enhancing quality of life for mesothelioma patients and their families in alignment with the aims and priorities of the Asbestos National Strategic Plan.

Victorian Mesothelioma Outcomes Registry

Overall Summary 2022-2024

301 people diagnosed with mesothelioma

19 Participating health services

77 Median age at diagnosis (years)

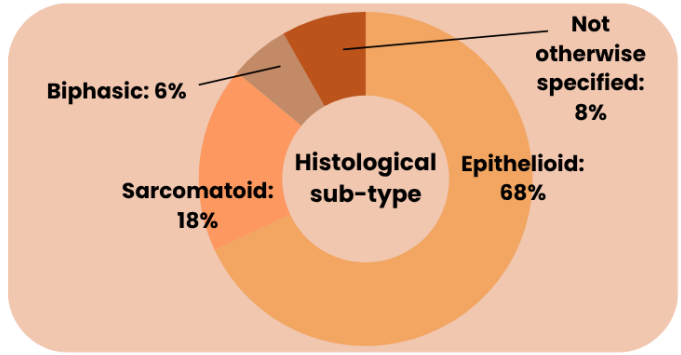
66% of participants diagnosed lived in metropolitan Victoria

64% of participants with history of **asbestos exposure** documented in their medical records

78% of participants were male and **22%** were female

92% of participants had **pleural** mesothelioma

One year survival of **37%**



62% of participants had a referral to diagnosis within 28 days

63% of participants had documented presentation at a multidisciplinary meeting

28% of participants had a documented specialist cancer nurse in their medical records

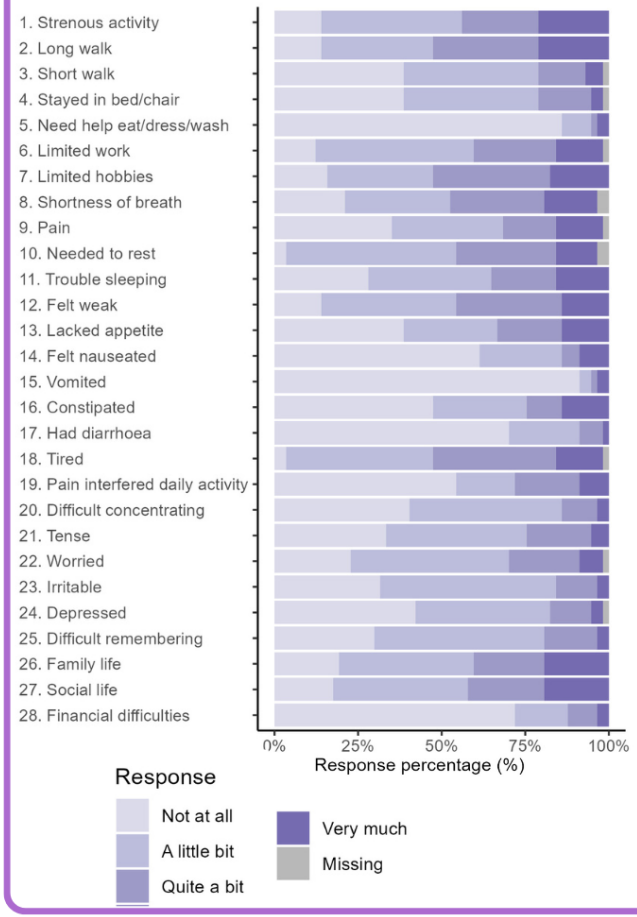
76% of participants had a documented performance status (ECOG)

57% of participants received systemic anti-cancer therapy (immunotherapy and/or chemotherapy)

Victorian Mesothelioma Outcomes Registry

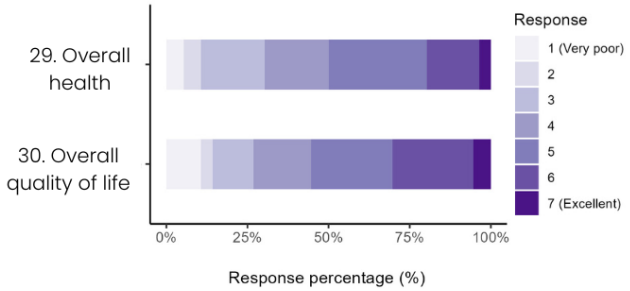
PROMs/PREMs Summary 2022-2024

Responses to PROMs (EORTC QLQC30)



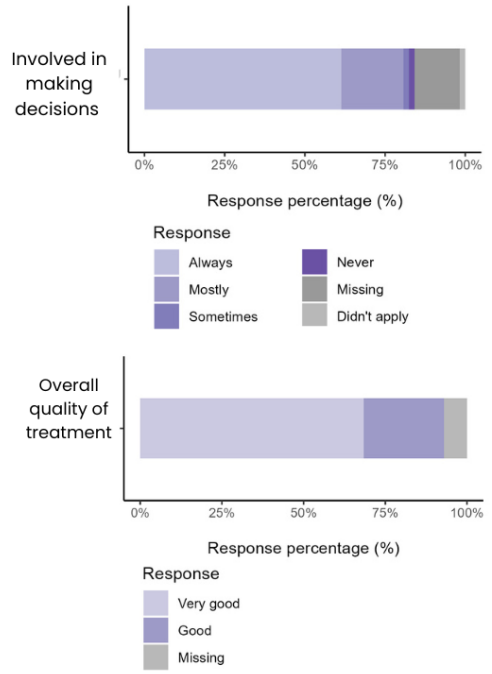
37% response rate to PROMs/PREMs survey

Responses to PROMs (EORTC QLQC30) cont.



61% of PREMs survey responders were given the name of a Clinical Nurse Specialist or Patient Navigator after their diagnosis

Responses to selected PREMs



91% of participants returned survey's by mail

9% of participants completed the survey online

Executive Summary

Key Clinical Findings

- **64%** of participants had documented history of asbestos exposure.
- **68%** of patients were diagnosed with epithelioid mesothelioma.
- **63%** of participants had documented presentation at a multidisciplinary meeting (MDM). This ranged from 54% to 81% across Victoria.
- **28%** of participants had access to a specialist cancer nurse for support, ranging from 25% to 35% across Victoria.
- **56%** of participants had systemic anti-cancer treatment [SACT] (immunotherapy and/or chemotherapy). However, this varied from 38% to 66% across Victoria.
- One-year overall survival was 37%.
- The median overall survival was 8.7 months.

Key PROMs/PREMs Findings

- Within the week prior to completing the PROMs survey, overall health (30%) and overall quality of life (28%) were ranked as somewhat poor, quite poor to very poor on a 7-point scale.
- For the week prior to PROMs survey completion the highest proportion of people reported being very much or quite a bit limited or troubled by the following fatigue-related symptoms: feeling tired (51%), unable to do strenuous activities (44%), needing to rest (42%) and feeling weak (46%).
- A high proportion also reported being very much or quite a bit limited in pursuing their hobbies (53%), or taking a long walk (53%) with their physical condition or medical treatment having an adverse impact on their family life (40%) and social life (42%).
- For PREMs, the majority thought the overall quality of their health service treatment was very good (61%) or good (9%) and were always (61%) or mostly (19%) involved as much as they wanted in decision making.
- 61% reported being aware that they or a family member had been exposed to asbestos in the past and 84% were aware that this was a compensatable disease.
- 58% reported that they had been symptomatic for over 2 months prior to their mesothelioma diagnosis, 28% reported symptoms for over 6 months.
- Interestingly, of those who responded, 80% received some form of SACT, in comparison to the 57% SACT rate identified from hospital medical records.

Recommendations

1. Earlier diagnosis: develop training and education modules to increase mesothelioma symptom awareness in primary health care professionals, respiratory and cancer specialist nurses and asbestos support group communities to accelerate referral for investigation and diagnosis following onset of symptoms.
2. Access to treatment and support navigating care pathways: address disparities in access to mesothelioma trained cancer nurse specialists and optimal systemic anti-cancer therapy across the state.
3. Research to improve therapeutic option and alleviate symptoms affecting quality of life: develop a state-wide mesothelioma multidisciplinary team and research network of trials and studies open to referrals from all cases diagnosed across the state.

Methods

VMOR Database

Data collection was conducted at each 19 participating health services by manual review of the medical records via REDCap (Research Electronic Data Capture) database platform. Once data collection was completed, data analysis was conducted using R programming language.

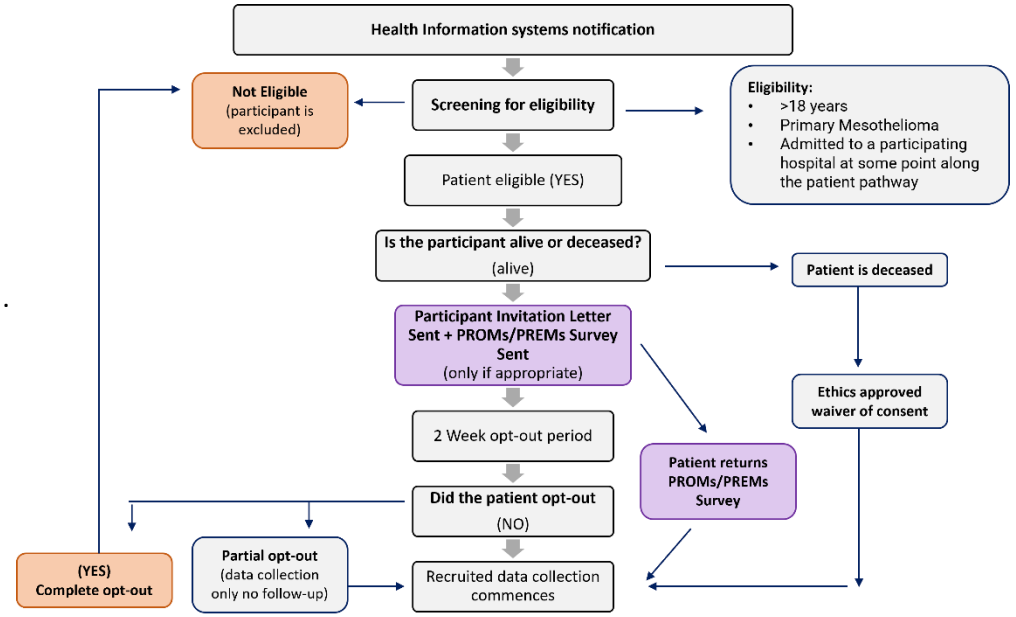
The VMOR REDCap database is a secure, web-based application. Data collected through REDCap will be stored on infrastructure located in Australia and managed by Helix (Monash University). Data stored on this infrastructure is backed up daily and encrypted. The data is accessed securely and stored via Monash University Helix Serves**.**

- The VMOR is a sub-project of the Victorian Lung Cancer Registry (VCLR). The VMOR received ethics approval from Monash University Human Research Ethics Committee (MUHREC) and governance approval at 19 participating health services to collect data.
- 301 cases notified via the hospital administrative data notifications sent to the VLCR.
- The PROMs/PREMs survey was sent to participants along with the invitation letter.
- Participants completed the survey primarily by mail, with some opting for electronic submission or phone interviews.

Participating Health Services

- Albury-Wodonga Health
- Alfred Health
- Austin Health
- Grampians Health
- Barwon Health
- Bendigo Health
- Cabrini Health
- Eastern Health
- Epworth Healthcare
- Goulburn Valley Health
- Latrobe Regional Health
- Monash Health
- Northern Health
- Peninsula Health
- Peter MacCallum Cancer Centre
- Royal Melbourne Hospital
- St Vincent's Hospital
- St Vincent's Private Hospital
- Western Health

Figure 1: Participant recruitment and screening process



Demographics and diagnostic indicators

- **301** people diagnosed with mesothelioma were recruited to VMOR.
- The majority of people diagnosed with mesothelioma were male (78%) and the median age at diagnosis was **77** years (IQR: 69, 83).
- Mesothelioma participants were more likely to live in metropolitan areas (66%).
- **14%** of participants were from a relatively disadvantaged area (IRSAD* quintile 1).
  **The Index of Relative Socio-economic Advantage and Disadvantage (IRSAD)*

64% of participants with history of **asbestos exposure** documented in their medical records

- **64%** of participants had documentation of prior asbestos exposure in their medical record and **1%** had a past history of radiation.
- **92%** of participants had pleural mesothelioma, compared to **8%** who had peritoneal mesothelioma.
- Epithelioid was the most common histological sub-type (**68%**), followed by sarcomatoid (**18%**) and biphasic **(6%**) mesothelioma.

Figure 2: Histological subtype

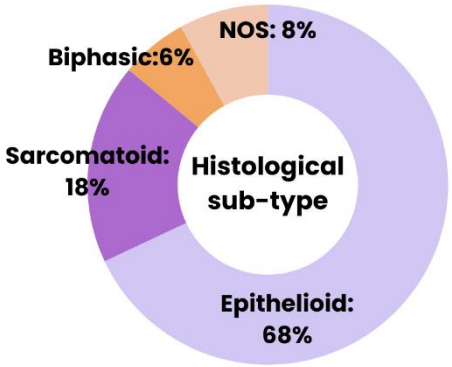


Figure 3: Type of mesothelioma

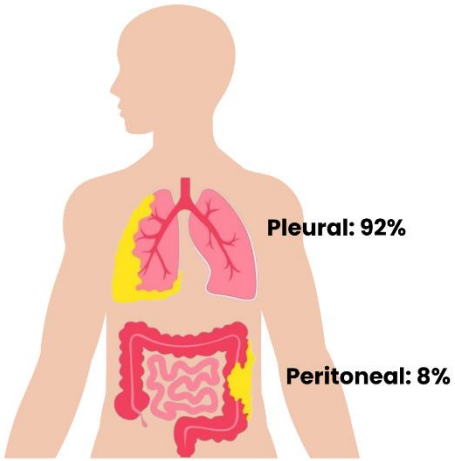


Figure 4: Age (years) at diagnosis

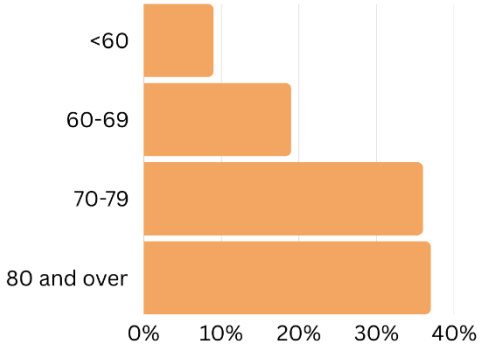
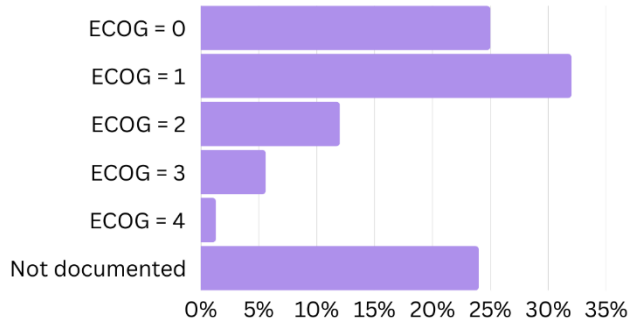


Figure 5: Documented ECOG performance score

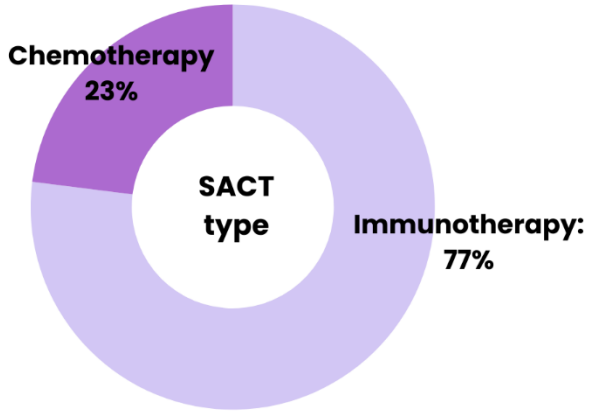


- **62%** of participants had a referral to diagnosis within 28 days, ranging from 52% to 76% across Victoria.

Management and treatment indicators

- Approximately **63%** of all participants had a documented presentation at a multidisciplinary meeting, ranging from 54% to 81% across Victoria.
- **28%** of participants had access to a specialist cancer nurse for support, ranging from 25% to 35% across Victoria.
- Similarly, **28%** of participants had documented supportive care screening, ranging from 15% to 43% across Victoria.
- For people with pleural mesothelioma, **25%** had a record of definitive up front effusion management (with pleurodesis).

Figure 6: Systemic anti-cancer therapy received



28% of participants had access to specialist cancer nurse for support

28% of participants had documented supportive care screening

25% of participants had definitive effusion management

- **63%** of participants living with mesothelioma received some form of active treatment (chemotherapy, immunotherapy, radiotherapy or radical surgery).
- **57%** of participants received SACT, ranging from 38% to 66% across Victoria.
  - ❖ Of those who had SACT, **77%** received first line treatment regimes including immunotherapy.
- **5%** of participants had radical surgery and **12%** had radiotherapy.

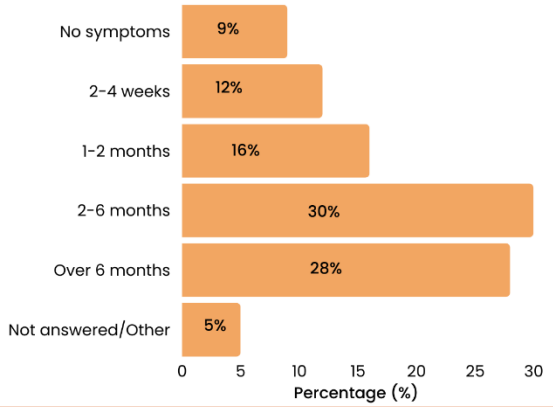
PROMs and PREMs

37% response rate to PROMs/PREMs survey

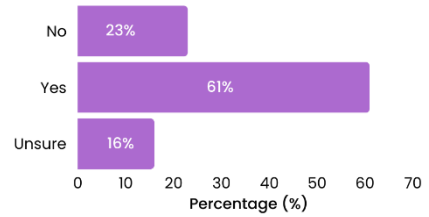
91% of participants returned survey's by mail

9% of participants completed the survey online

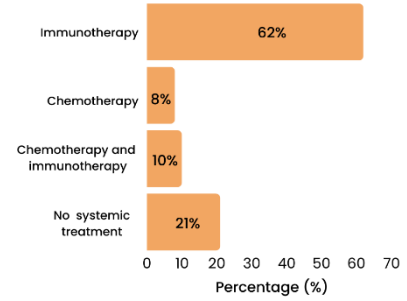
How long did you have symptoms before you were diagnosed with mesothelioma?



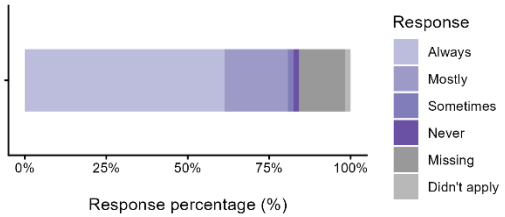
Have you or your spouse, or any member of your family been exposed to asbestos, to your knowledge?



What systemic therapy treatment have you received?



Involved in making decisions



Overall quality of treatment

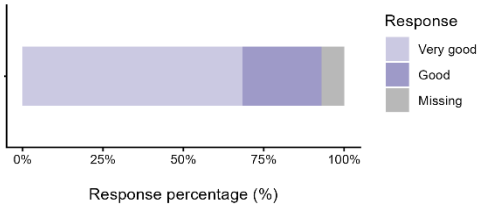
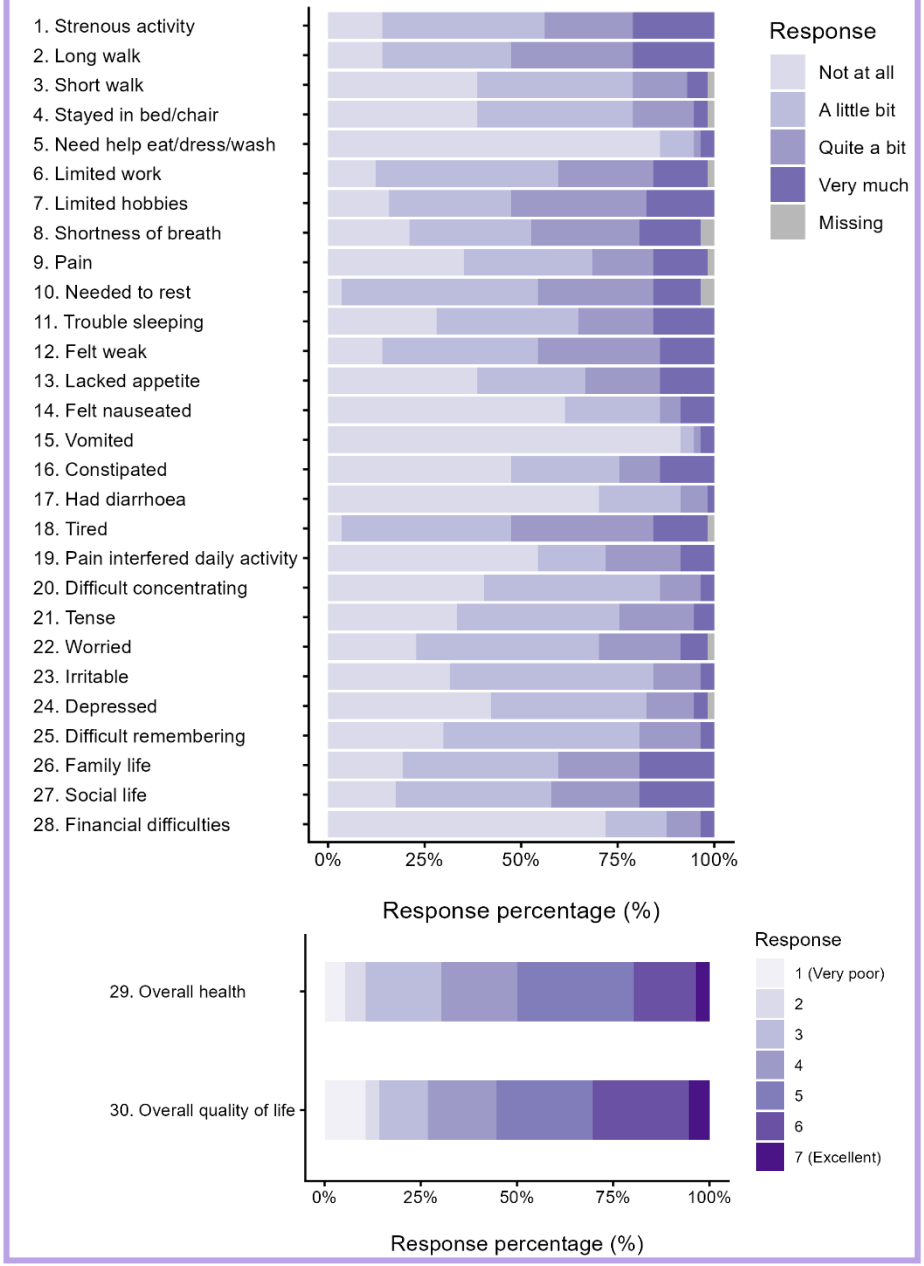


Figure 8: Results of the EORTC QLQC-30



Survival

- The one-year overall survival rate was 37% (95% CI: 31%–45%), with a median survival of 8.7 months.
- One-year overall survival was 50.7% (95%CI: 32.7 to 78.8) for participants receiving first-line SACT and median survival was 14 months.
- Survival was significantly higher for participants receiving first-line treatment compared to those who did not receive SACT (HR: 0.24, 95%CI: 0.18 to 0.33, p-value <0.001).
- The median survival time was 11 months for patients with epithelioid mesothelioma and 5.6 months for those with non-epithelioid mesothelioma.
- Patients with non-epithelioid mesothelioma had a significantly higher mortality rate (HR 2 [1.4–2.85]) compared to those with epithelioid mesothelioma.

Figure 9: Overall survival from diagnosis date

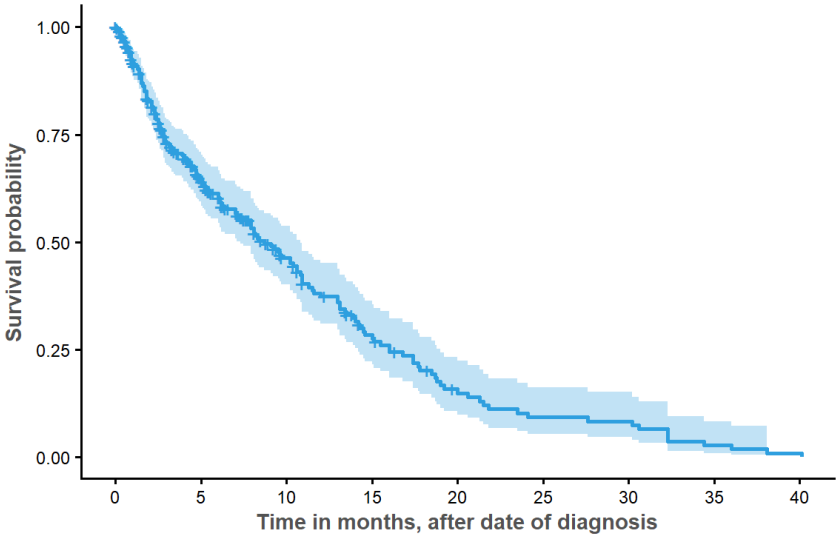
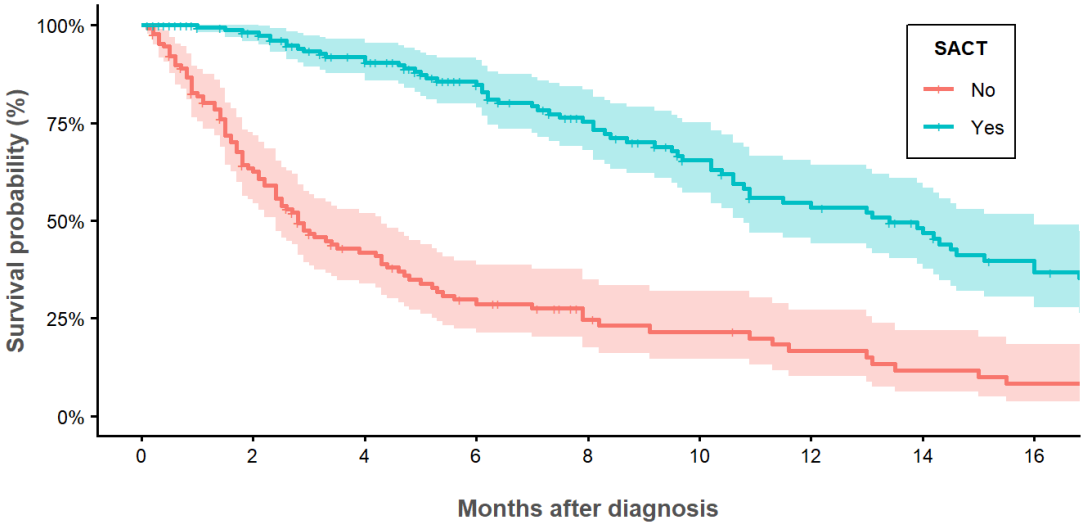


Figure 10: Overall survival stratified by receipt of first-line SACT



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Associate Professor Robert Stirling (VLCR Clinical Lead)

Mesothelioma Steering Committee:
Susan Harden, John Zalcberg, Robert Stirling, Brian Healy, Karen Healy, Vicki Hamilton (CEO/Secretary Asbestos Council of Victoria/Gippsland Asbestos Related Disease Support Inc Silicosis), Ewan MacFarlane,
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References

1. Asbestos and Silica Safety and Eradication Agency. Asbestos National Strategic Plan 2024-2030. 2024. Australian Government, Canberra
2. Department of Health. Victorian cancer plan 2024-2028. Victoria State Government. 2024. Melbourne.
3. Aaronson NK, Ahmedzai S, Bergman B, Bullinger M, Cull A, Duez NJ, et al. The European Organization for Research and Treatment of Cancer QLQ-C30: a quality-of-life instrument for use in international clinical trials in oncology. J Natl Cancer Inst. 1993;85(5):365-76.
4. Harden S, Tissera S, Lloyd M, Stirling R. Patterns of care, clinical outcomes and patient reported measures for people diagnosed with mesothelioma in Victoria. Asia-Pacific Journal of Clinical Oncology 2024 Nov 1 (Vol. 20, pp. 193-194).
5. O'Callaghan C, Brooker J, Tissera S, Samankula D, Healy B, Healy K, Hamilton V, Philip J, Stirling R, Zalcberg J, Schofield P, Harden S. Co-Designing a Quality of Life Survey for Mesothelioma: Qualitative and Cognitive Interview Findings. J Pain Symptom Manage. 2025 Nov;70(5):401-409. doi: 10.1016/j.jpainsymman.2025.07.0046
6. Harden S, Samankula D, Tissera S, Brand M, Lloyd M, Zalcberg J Stirling R, The Victorian Mesothelioma Outcomes Registry Annual Report, 2022. Monash University, School of Public Health and Preventive Medicine, Report No 1, pages 13.

Appendix: Benchmarked clinical quality indicators

CQI 1: Referral to diagnosis time within 28 days
CQI 2: Documented management discussion at a multi-disciplinary meeting (MDM)
CQI 3: Documented asbestos exposure history
CQI 4: Documented histologic subtype of mesothelioma on pathology report
CQI 5: Documented performance status (ECOG)
CQI 6: Received Firstline Systemic Anticancer therapy (chemo/immunotherapy)
CQI 7: Access to cancer specialist nurse for support
CQI 8: Documented supportive care screening
CQI 9: Definitive up front effusion management

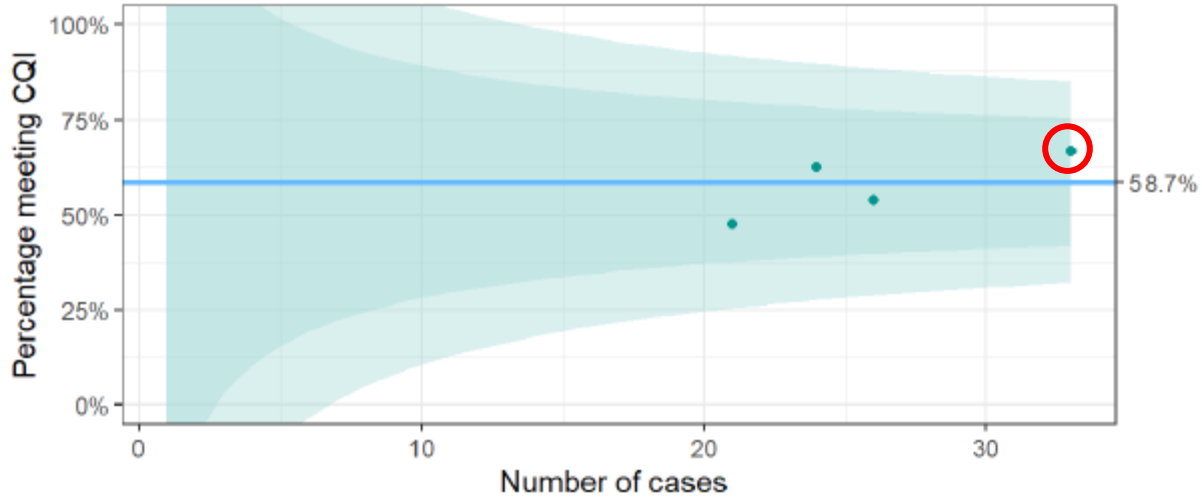
Each CQI is reported by Victorian Integrated Cancer Service (VICS) groupings (Table 1) as opposed to health service due to the sample size and should be viewed as exploratory. In the graph, each VICS grouping is represented by a dark green dot, with your specific ICS highlighted by a red circle. (Figure 8). The solid line represents the median proportion of participants meeting the indicator. The shaded areas represent the 95% and 99.8% control limits. The dark orange box displays the median percentage from 2022 for comparison.

Table 1: Distribution of people living with mesothelioma by Victorian Integrated Cancer Services

Victorian Integrated Cancer Services (VICS)	VMOR Participating Health Services
Southern Melbourne Integrated Cancer Service (SMICS)	Alfred Health, Cabrini Health, Monash Health, Peninsula Health.
Western and Central Melbourne Integrated Cancer Service (WCMICS)	Peter MacCallum Cancer Centre, Royal Melbourne Hospital, St Vincent's Private Hospital, St Vincent's Public Hospital, Western Health
North Eastern Melbourne Integrated Cancer Service (NEMICS)	Epworth Health, Austin Health, Eastern Health, Northern Health.
Regional Integrated Cancer Services *	Barwon Health, Grampians Health, Latrobe Regional Health, Albury Wodonga Health, Goulburn Valley Health, Bendigo Health.

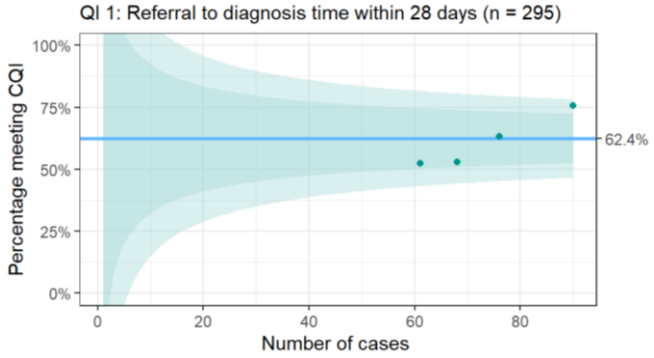
**Barwon South Western Integrated Cancer Services (BSWRICS), Grampians Integrated Cancer Services (GICS), Gippsland Regional Integrated Cancer Service (GRICS), Hume Regional Integrated Cancer Services (HICS), and Loddon Mallee Integrated Cancer Service (LMICS).*
Note: Regional ICS included combined health services due to low case numbers

Figure 8: Example clinical quality indicator graph

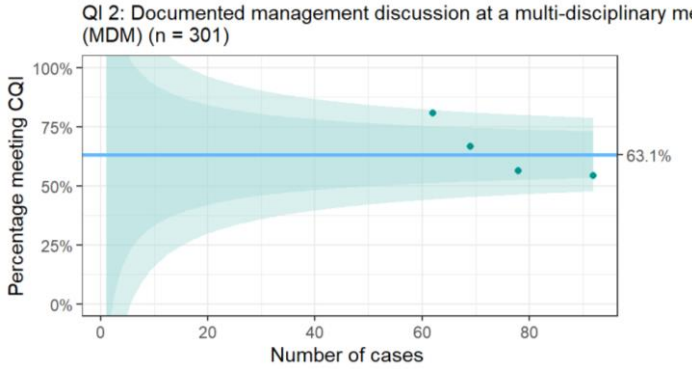


Appendix: Clinical quality indicators

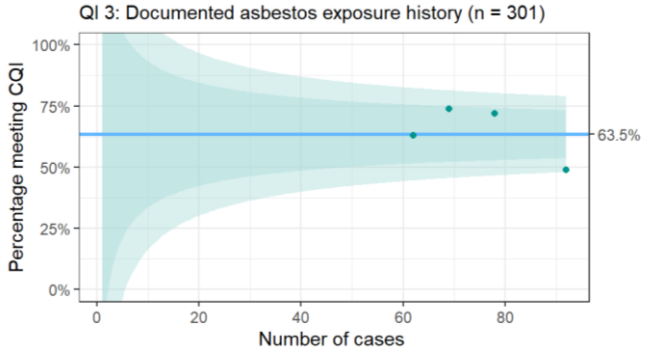
Graphs: Clinical Quality Indicators



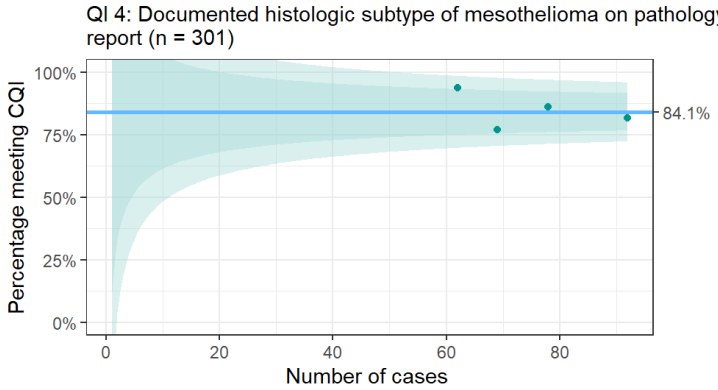
62.4 of participants were diagnosed within 28 days of referral, ranging from 52% to 76%.



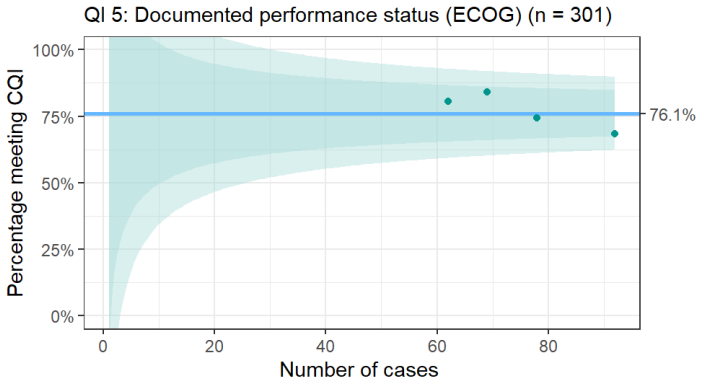
63.1 of participants had a documented multi-disciplinary meeting, ranging from 54% to 81%.



63.5% of participants had a documented asbestos exposure history, ranging from 49% to 74%.



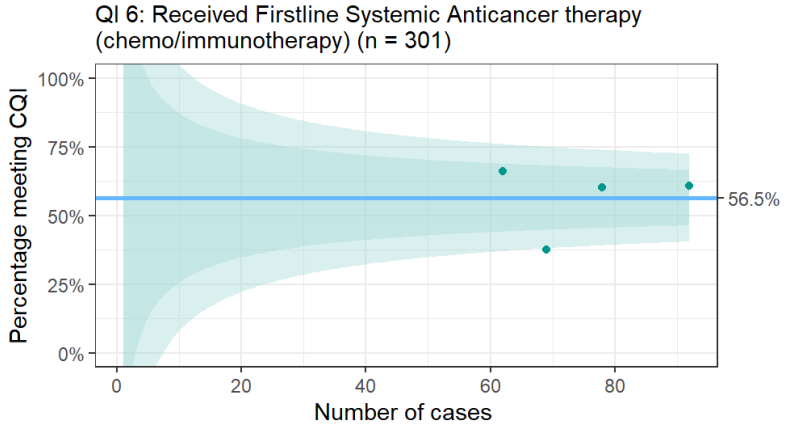
84.1% of participants had a documented histological subtype of mesothelioma, ranging from 77% to 94%.



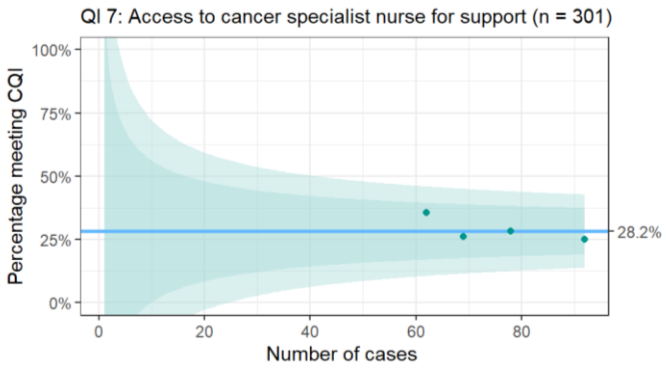
76.1% of participants had a documented performance status (ECOG), ranging from 68% to 81%.

Appendix: Clinical quality indicators

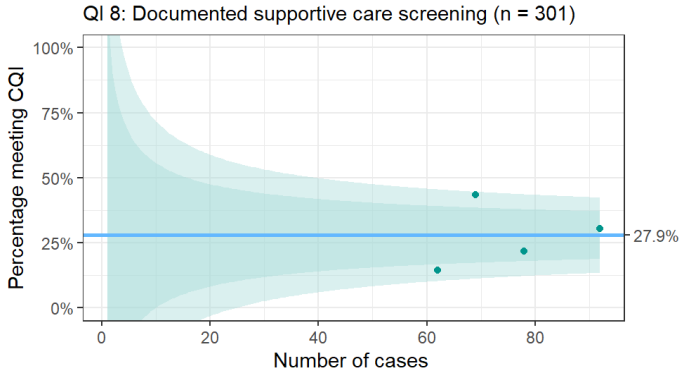
Graphs: Clinical Quality Indicators continued



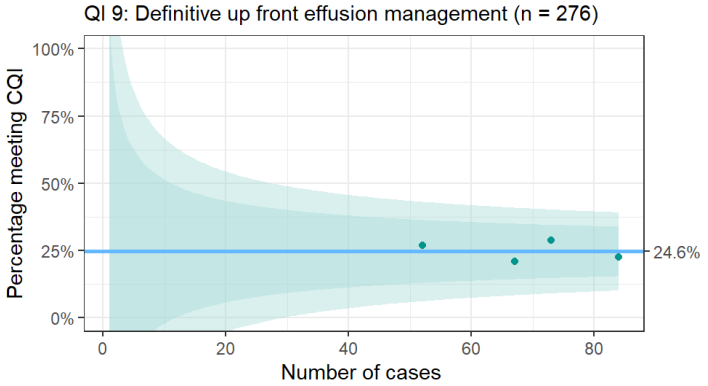
56.5% of participants received first-line SACT, ranging from 38% to 66%.



28.2% of participants had access to a cancer specialist nurse for support, ranging from 25% to 35%.



27.9% of participants had documented support care screening, ranging from 15% to 43%.



24.6% of participants had definitive up front effusion management*, ranging from 21%to 29%.

**For patients with pleural mesothelioma only. This indicator is novel.*