SITE REPORT

[redacted]

For period ending 1 April 2024

Prepared April 2024

Myeloma and Related Diseases Registry team

Monash University

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Introduction

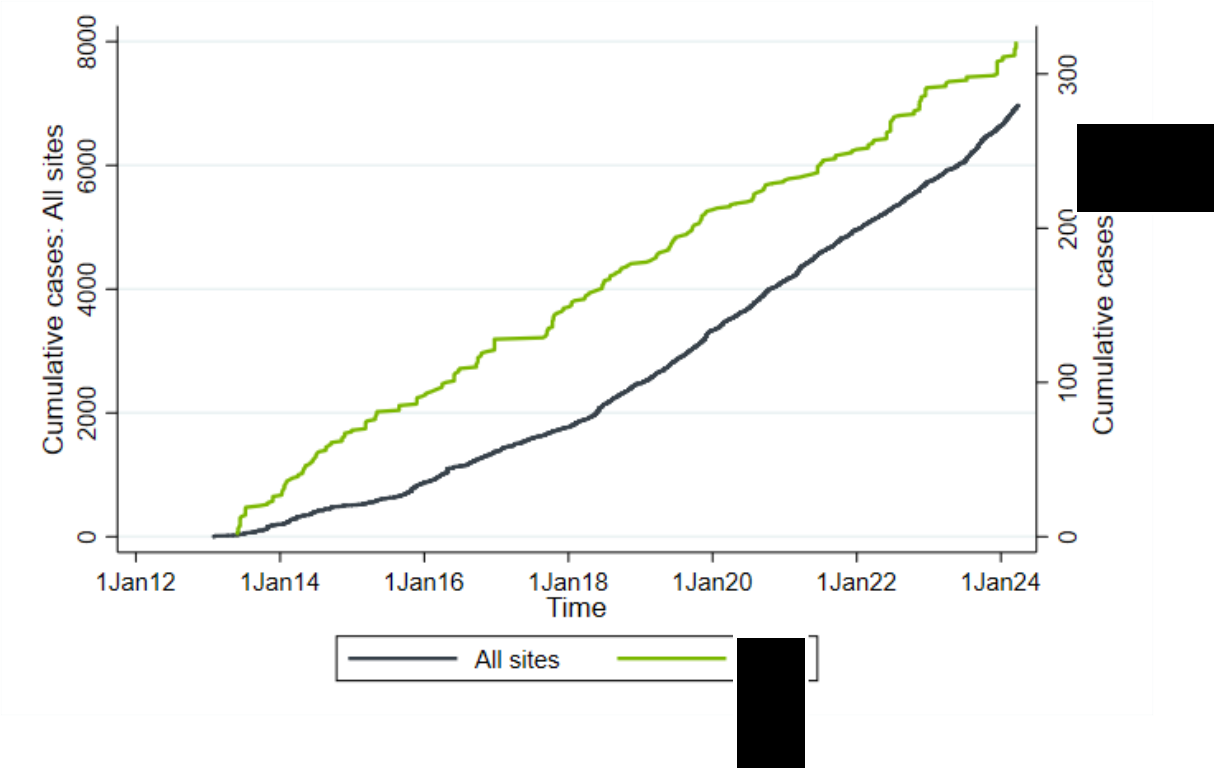
This report contains a summary of data from the Myeloma and Related Diseases Registry (MRDR) for the period 21 January 2013 to 1 April 2024. We provide some comparisons between data obtained from your site, other sites in Australia and sites in New Zealand.

The usefulness of the registry relies on the quality and completeness of the data obtained from our partner sites. As cases continue to accrue and follow-up continues, the registry provides a better reflection of clinical practice in relation to the treatment of multiple myeloma at your site, other sites in Australia and sites in New Zealand. We thank you for supporting the registry.

Case Accrual

As of 1 April 2024 there were 7048 patients registered on the MRDR.

Case accrual to 1 April 2024 for the MRDR. Cases from your site are shown in green, whilst the grey line gives cases for the entire registry. Note that the scale for your site is on the right y-axis and that for the combined sites is on the left y-axis.



Site status at time of report

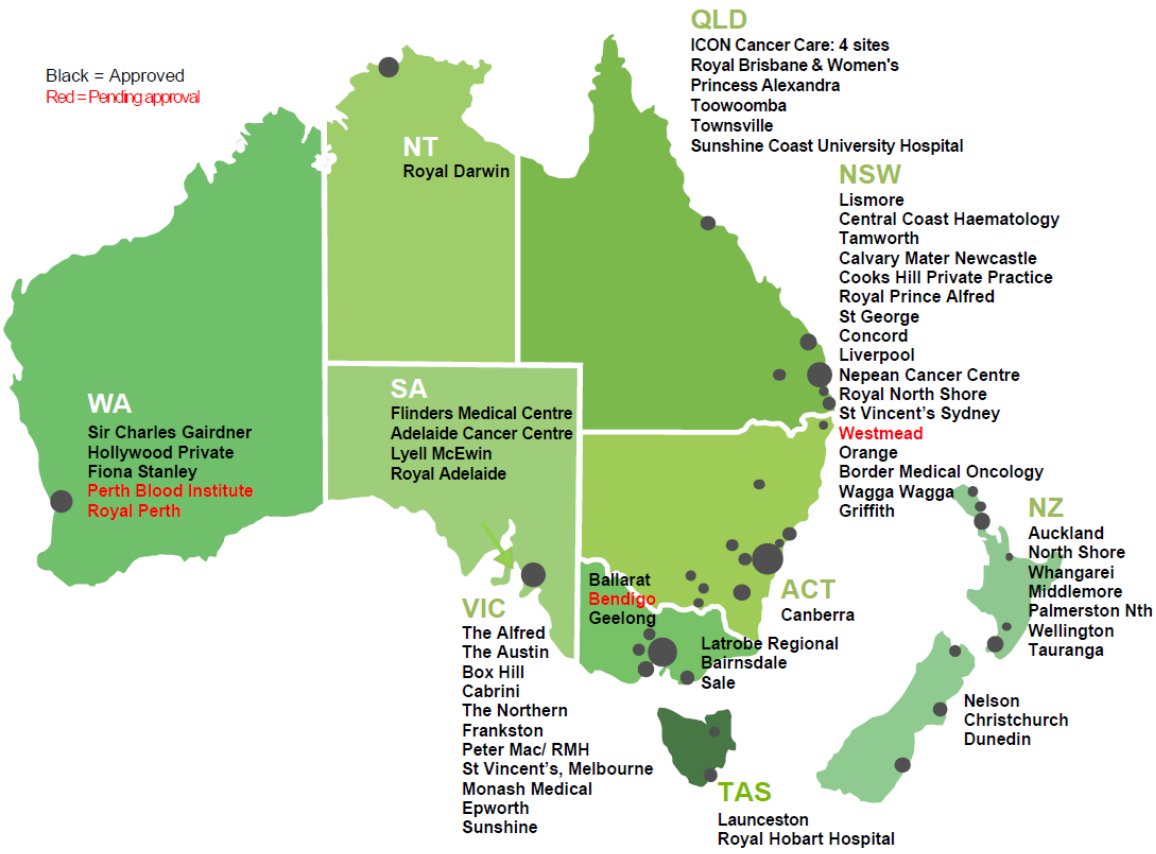
MRDR Sites

No. of patients in registry: 7048
No. of HREC approved sites: 59
No. of active sites: 53
No. of sites w. ethics/governance pending: 4

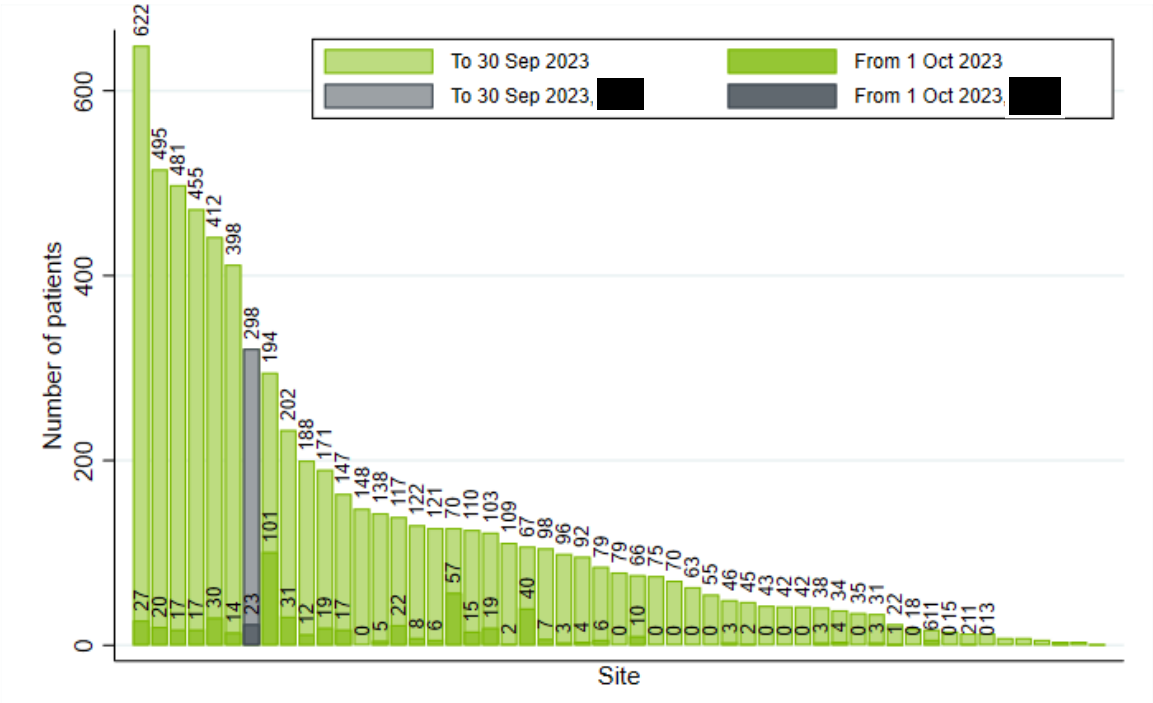
Myeloma 1000 biobank sites

No. of M1000 patients in registry: 676
No. of HREC approved sites: 16
No of active sites: 13
No. of sites with ethics/governance pending: 2

Hospital sites in Australia and New Zealand



Number of patients registered on the MRDR by site. We show sites in descending order of total registrations. The dark bars show the number of patients registered since the last site report (1 October 2023) and the light bars show the number of patients registered prior to this. For clarity, bar labels are not displayed for sites with a total of less than ten registrations.



Patient characteristics

Breakdown of diagnoses from your site, other sites in Australia and sites in New Zealand

All patients	Your site	Aus (Excl. [redacted])	New Zealand
N	281	4967	1416
Diagnosis			
Multiple myeloma (MM)	255/281 (90.7%)	3572/4967 (71.9%)	1133/1416 (80.0%)
MGUS/Smouldering MM	16/281 (5.7%)	1298/4967 (26.1%)	261/1416 (18.4%)
Plasma cell leukemia	6/281 (2.1%)	25/4967 (0.5%)	9/1416 (0.6%)
Solitary bone plasmacytoma	2/281 (0.7%)	52/4967 (1.0%)	7/1416 (0.5%)
Solitary extramedullary plasmacytoma	2/281 (0.7%)	20/4967 (0.4%)	6/1416 (0.4%)

MGUS = monoclonal gammopathy of undetermined significance.

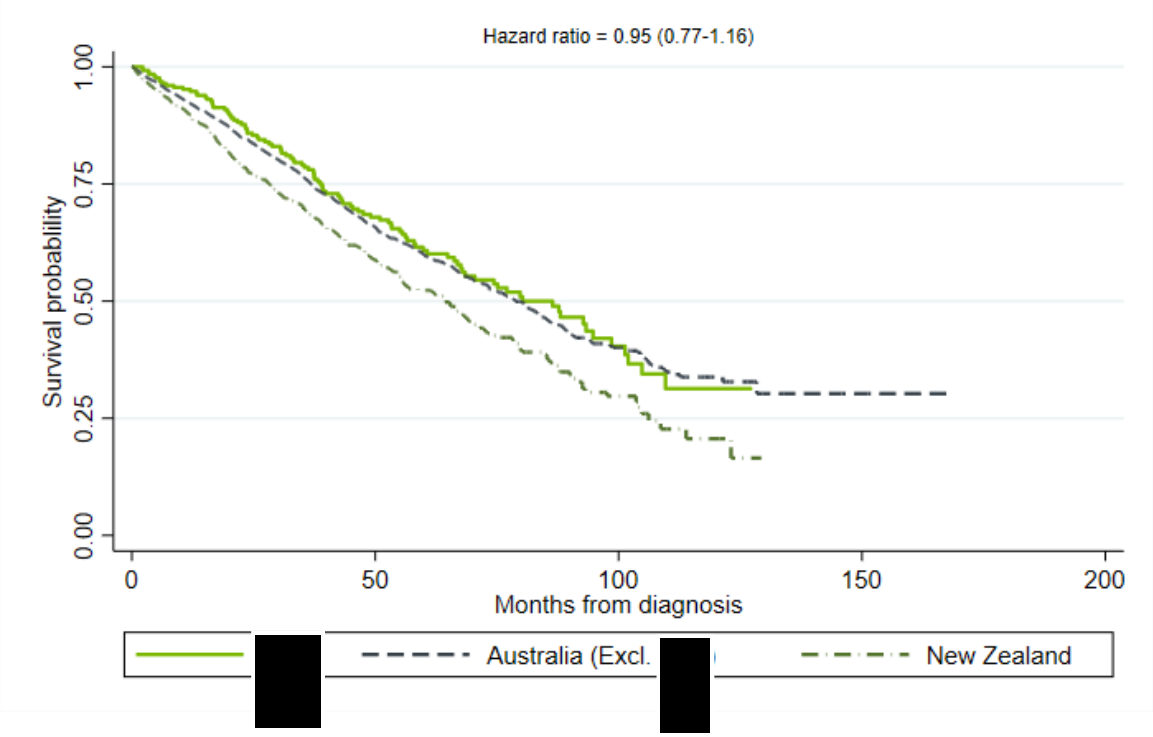
Demographic and clinical statistics for patients with multiple myeloma (MM) or plasma cell leukaemia (PCL) at your site compared with other sites in Australia and sites in New Zealand. With the exception of mortality (updated with linkage to the National Death Index), values reflect data in the registry as of 1 April 2024.

MM and PCL patients	Your site	Aus (Excl. [redacted])	New Zealand
N	261	3597	1142
Age (years), median (IQR)	67.5 (58.0, 75.3)	68.0 (59.8, 75.6)	69.5 (61.1, 76.7)
Age >70 years, median (IQR)	104/261 (39.8%)	1517/3597 (42.2%)	542/1142 (47.5%)
Gender (Male)	153/261 (58.6%)	2209/3582 (61.7%)	675/1141 (59.2%)
Mortality	103/261 (39.5%)	1055/3597 (29.3%)	415/1142 (36.3%)
Received chemotherapy*	260/261 (99.6%)	3285/3597 (91.3%)	1035/1142 (90.6%)
Diagnosis to chemotherapy (days), median (IQR)	26.0 (9.0, 42.0)	18.0 (7.0, 34.0)	16.0 (6.0, 35.0)
ASCT†	109/150 (72.7%)	1287/1679 (76.7%)	332/529 (62.8%)
<65 years at diagnosis	85/98 (86.7%)	955/1171 (81.6%)	261/367 (71.1%)
65-70 years at diagnosis	24/52 (46.2%)	332/508 (65.4%)	71/162 (43.8%)
Diagnosis to ASCT (days), median (IQR)	193.0 (167.0, 220.0)	195.0 (161.0, 249.0)	232.5 (183.0, 290.0)
Bisphosphonate therapy	200/261 (76.6%)	2162/3597 (60.1%)	710/1142 (62.2%)
Thromboprophylaxis	167/261 (64.0%)	1304/3597 (36.3%)	492/1142 (43.1%)
Antibiotic prophylaxis	186/261 (71.3%)	2067/3597 (57.5%)	840/1142 (73.6%)
Patients with progressions	149/261 (57.1%)	1339/3597 (37.2%)	447/1142 (39.1%)
EQ5D VAS**	80.0 (75.0, 90.0)	70.0 (50.0, 80.0)	70.0 (60.0, 80.0)

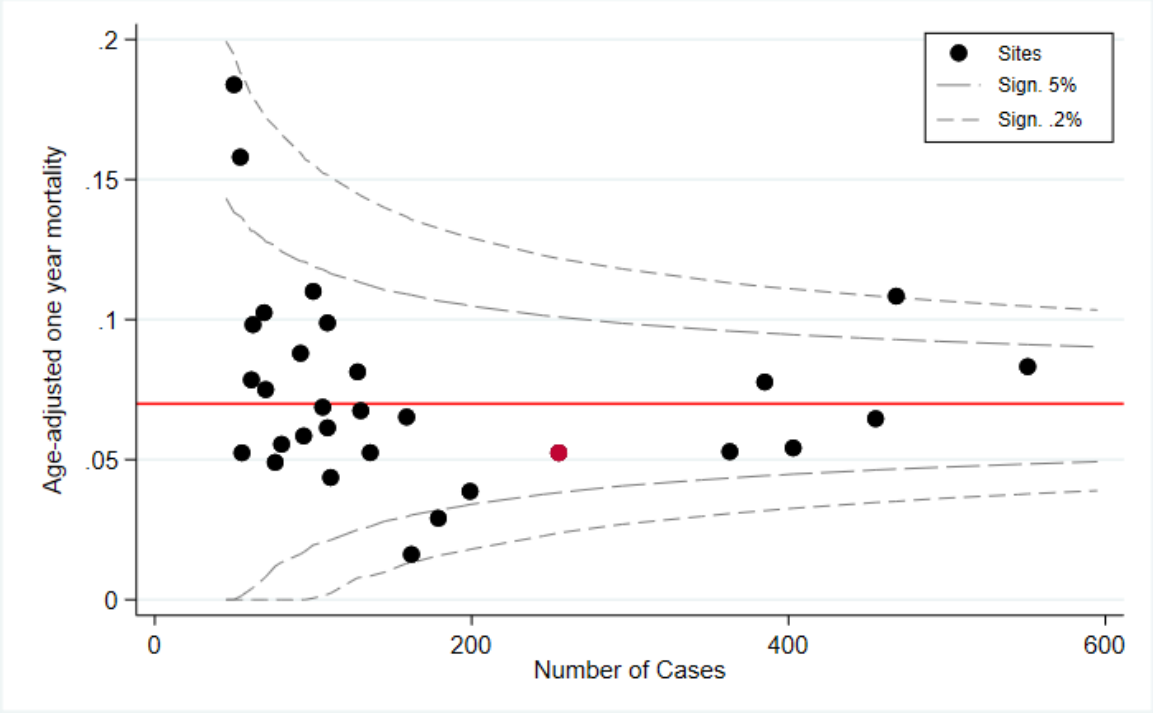
Values are expressed as N (%) or median (interquartile range). Patients with chemotherapy data on the registry. †Patients with age ≤ 70, at least 1 year post-diagnosis and some post-registration follow-up. ASCT=Autologous stem cell transplant. **EQ VAS records the respondent's self-rated health on a 20 cm vertical, visual analogue scale with endpoints labelled 'the best health you can imagine' (100) and 'the worst health you can imagine' (0).

Survival time

Overall survival of MM and PCL patients at your site compared with other sites in Australia and sites in New Zealand. The hazard ratio (95% confidence interval), compares your site to other sites in Australia.

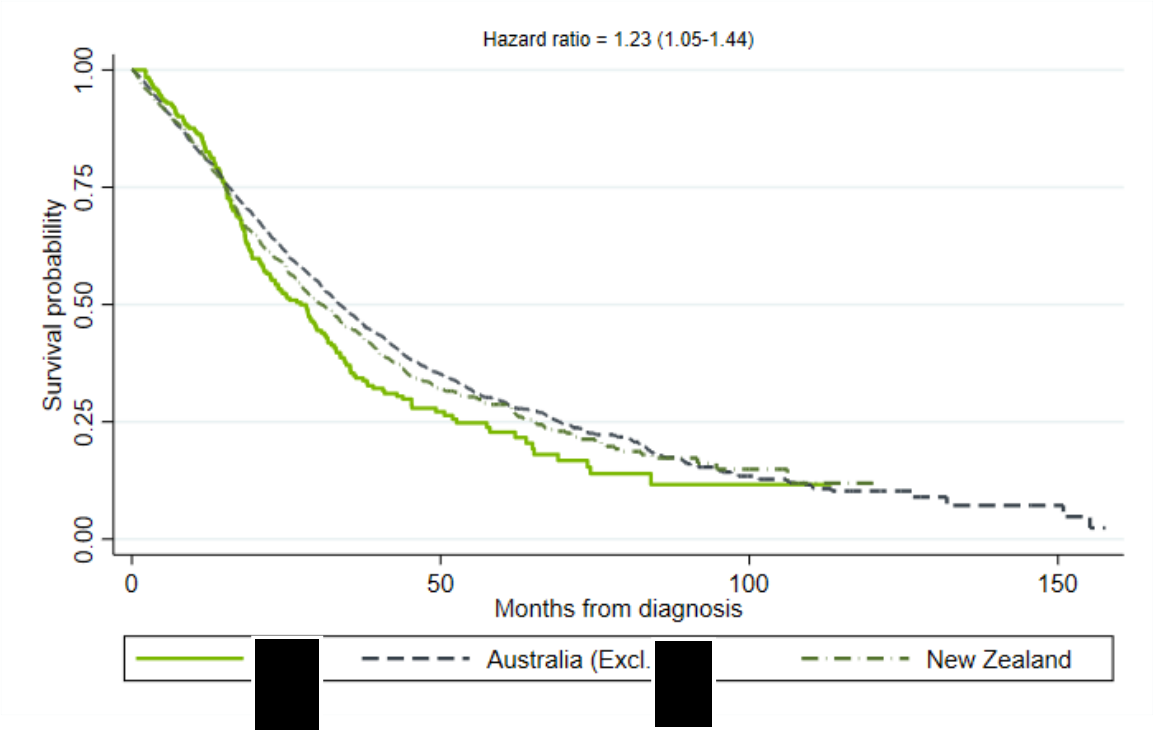


Funnel plot of age-adjusted one year mortality as a function of the number of eligible patients. Each point represents a separate site, the red line gives the weighted average of the age-adjusted one-year mortality across all sites. Points located above the line have higher than average mortality and those below the line lower than average, your site is plotted in red. The dashed lines represent significance levels of 5% and 0.2%. One-year mortality has been adjusted for age only, no other risk factors have been adjusted for due to data completeness issues.



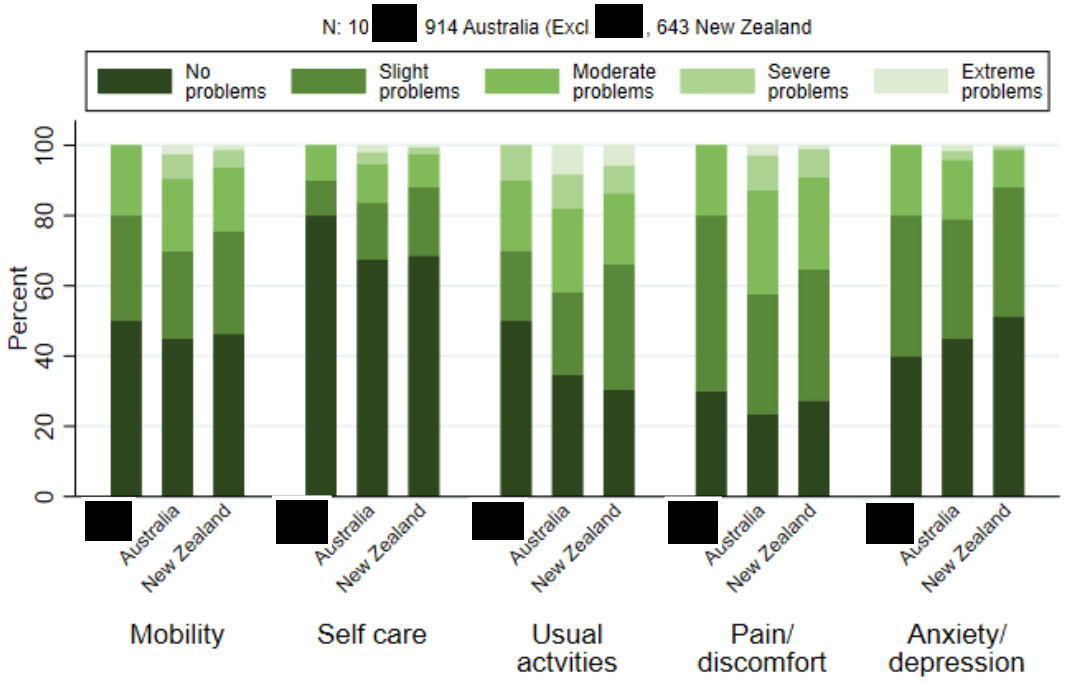
Time to disease progression

Progression-free survival of MM and PCL patients at your site compared with other sites in Australia and sites in New Zealand. The hazard ratio (95% confidence interval), compares your site to other sites in Australia.



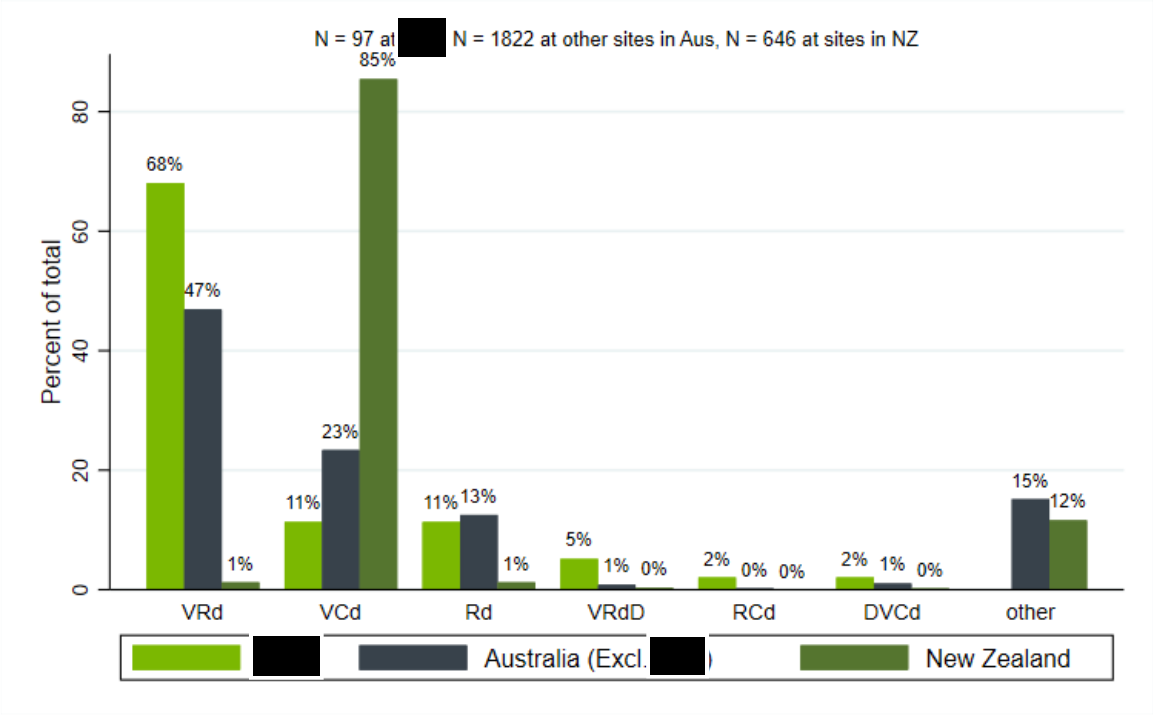
EQ5D results at diagnosis

A comparison of responses to the EQ5D patient survey taken at diagnosis between your site, other sites in Australia and sites in New Zealand. Each patient health domain, listed across the bottom of the graph, is scored on a five point scale of increasing problems.

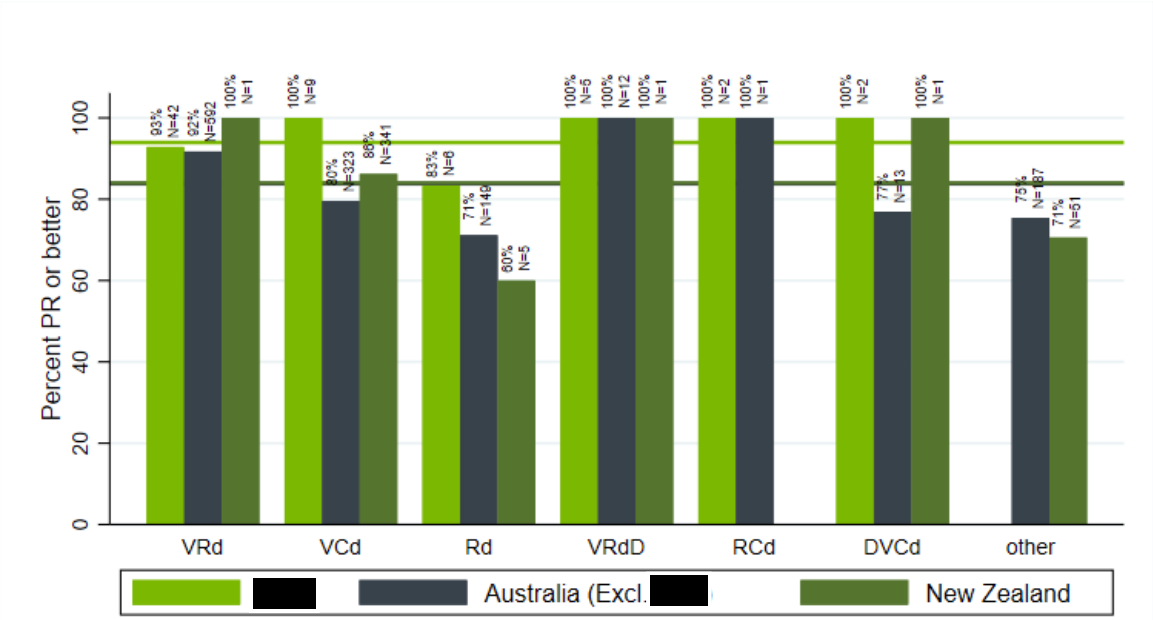


First-line treatment

Frequency of the most common combinations for first-line therapy in the last 5 years in MM and PCL patients for your site, other sites in Australia and sites in New Zealand. Note that due to rounding, percentages may not sum to 100%.

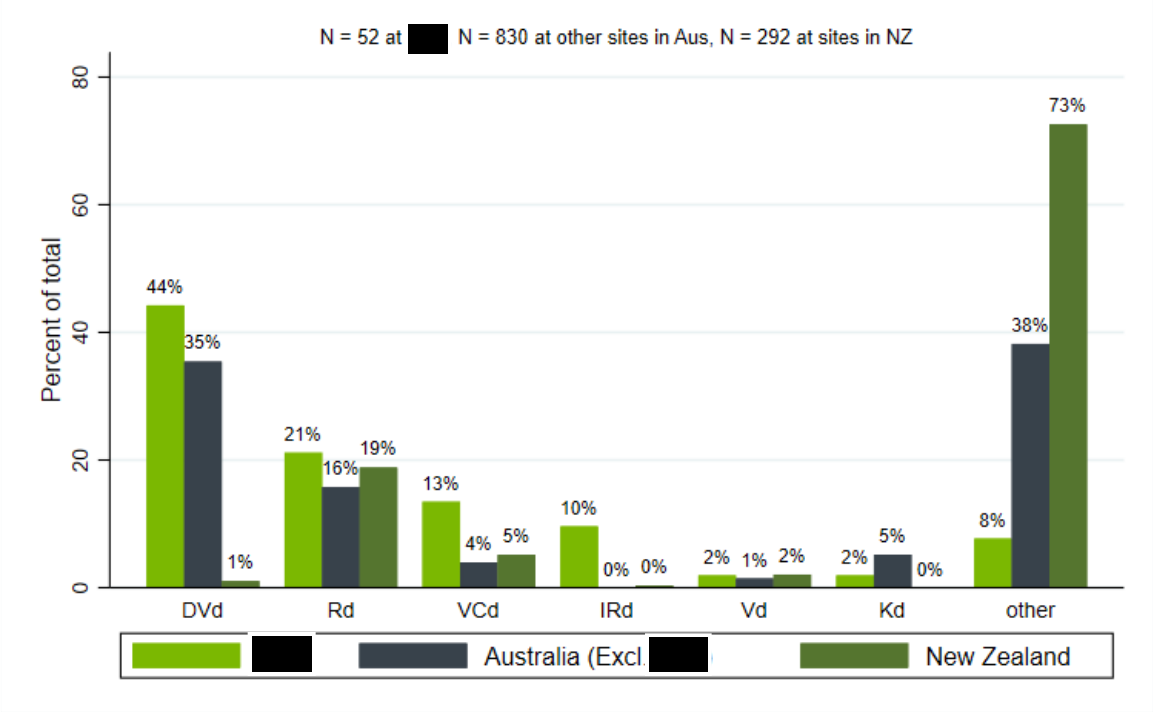


Response: percentage of MM and PCL patients achieving a partial response (PR) or better for common first-line therapy combinations. The light green line gives the average response rate for all first-line therapies at your site, the grey line gives the same for other sites in Australia, and the dark green line for sites in New Zealand.

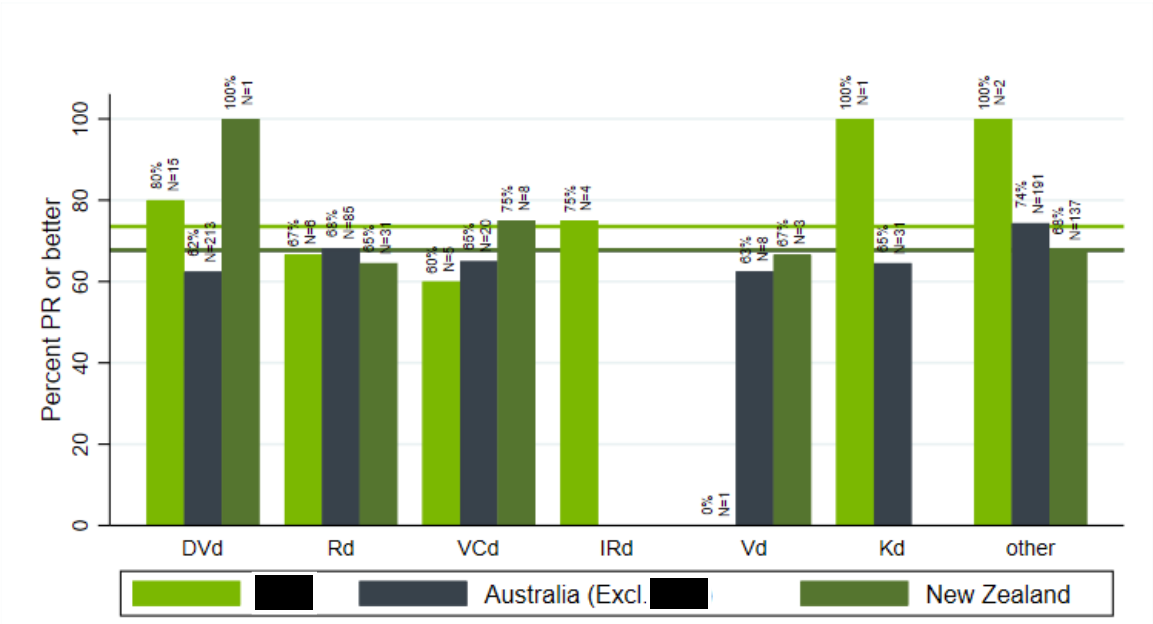


Second-line treatment

Frequency of chemotherapy regimens for the most common combinations for second-line therapy in the last 5 years in MM and PCL patients for your site, other sites in Australia and sites in New Zealand. Note that due to rounding, percentages may not sum to 100%. A list of the top 15 chemotherapy regimens is given in the appendix.

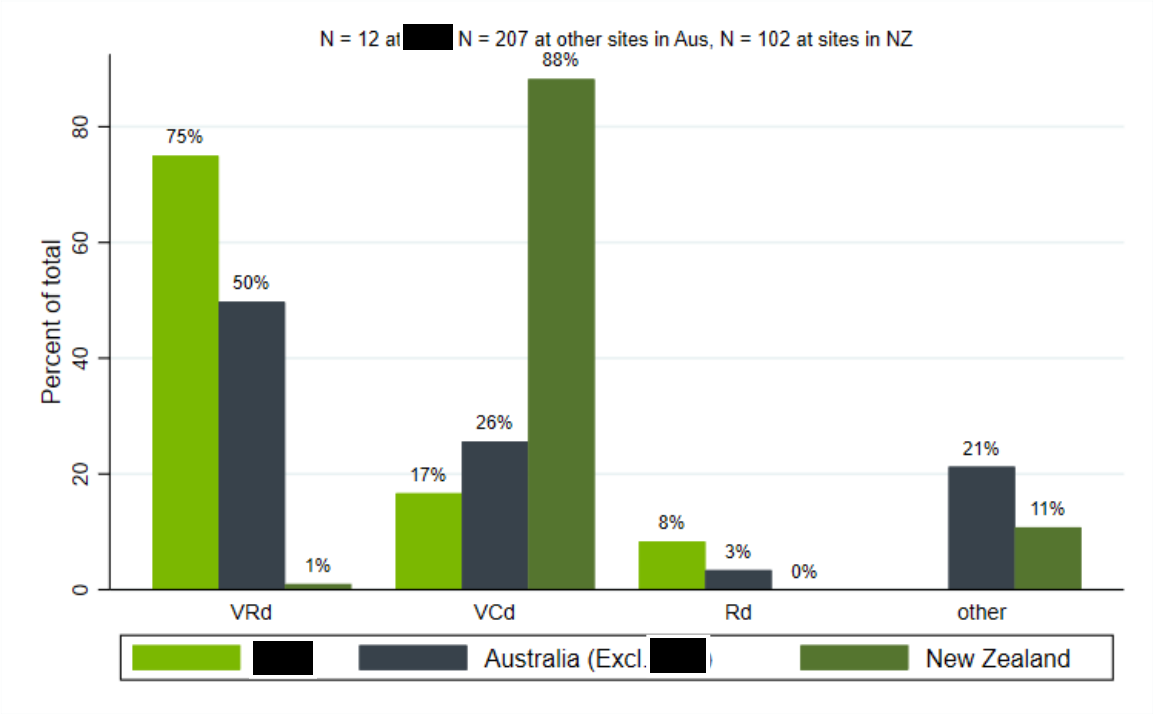


Response: percentage of MM and PCL patients achieving a partial response (PR) or better for common second-line therapy combinations. The light green line gives the average response rate for all second-line therapies at your site, the grey line gives the same for other sites in Australia, and the dark green line for sites in New Zealand.

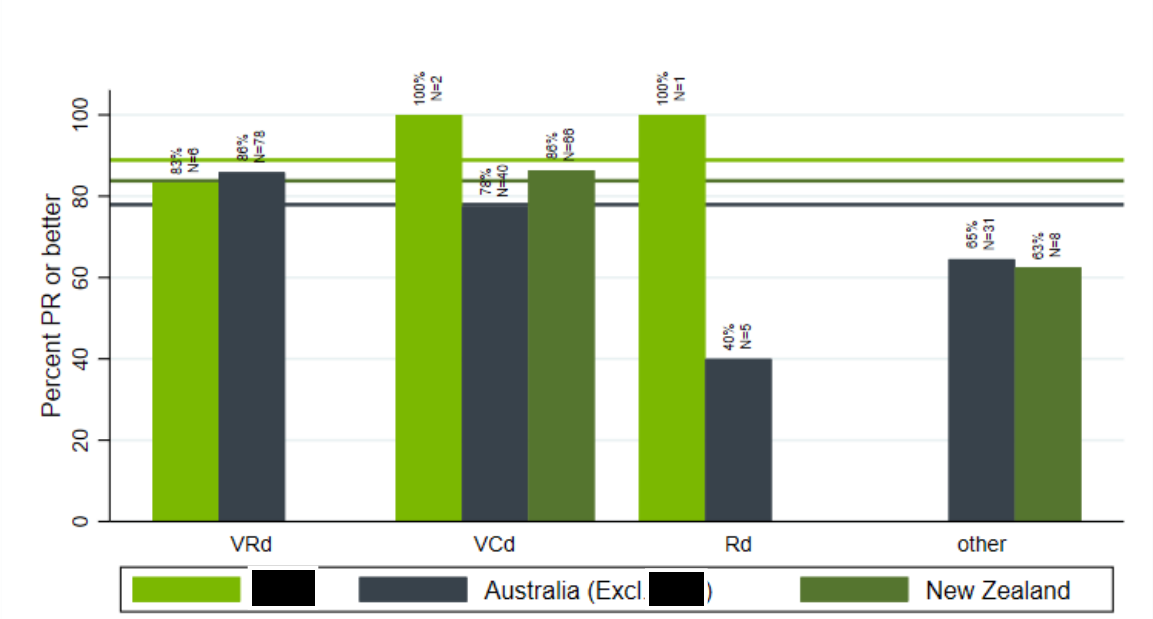


First line therapy for patients who did not receive an ASCT

Frequency of the most common combinations of first-line therapy in the last 5 years in MM and PCL patients who did not receive an ASCT for your site, other sites in Australia and sites in New Zealand. Note that due to rounding, percentages may not sum to 100%. To identify patients not for ASCT we only consider patients aged ≤ 70, at least 1 year post-diagnosis and with some post-registration follow-up.

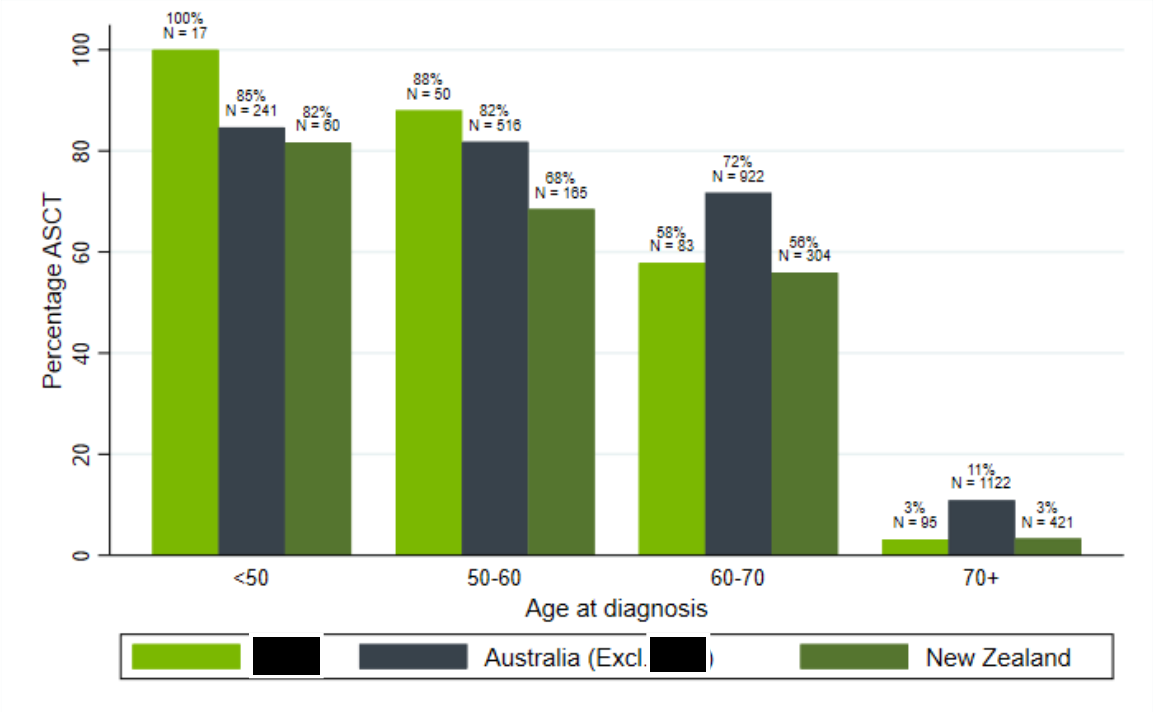


Response: percentage of MM and PCL patients who did not receive an ASCT achieving a partial response (PR) or better for common first-line therapy combinations. The green line gives the average response rate for all first-line therapies for these patients at your site, the grey line gives the same for other sites in Australia, and the dark green line for sites in New Zealand. To identify patients not for ASCT we only consider patients aged ≤ 70, at least 1 year post-diagnosis and with some post-registration follow-up.



ASCT therapy per age group

A comparison of the proportion of MM and PCL patients receiving ASCT at your site compared to other sites in Australia and sites in New Zealand. (Patients at least 1 year post-diagnosis, with some follow-up data post-registration)



Summary of data completeness

All patients	Your site	Aus (Excl.	New Zealand
N	321	5215	1438
1. No diagnosis	40/321 (12.5%)	248/5215 (4.8%)	22/1438 (1.5%)
2. No chemotherapy	0/248 (0.0%)	259/3349 (7.7%)	96/1067 (9.0%)
3. No ASCT	4/150 (2.7%)	218/1919 (11.4%)	50/559 (8.9%)
4. No supportive care	16/241 (6.6%)	564/3271 (17.2%)	126/1036 (12.2%)
5. No review	0/248 (0.0%)	216/3480 (6.2%)	50/1104 (4.5%)
6. No review in the last 18 months	16/138 (11.6%)	541/1673 (32.3%)	40/520 (7.7%)

1. No diagnosis entered on MRDR; 2. MM or PCL, registration > 6 months ago and no chemotherapy entered on MRDR; 3. MM or PCL, diagnosis > 1yr ago, age ≤ 70, no ASCT entered on MRDR and 'Not planned' for ASCT is not indicated in Review section; 4. MM or PCL, diagnosis > 1yr ago and no supportive care entered on MRDR; 5. MM or PCL diagnosed > 6 months ago and no review created on MRDR; 6. MM or PCL, registered > 18 months ago and no review entered on MRDR in the last 18 months

Thank you

The usefulness of these reports is enhanced by the quality and completeness of the data. Thank you for your contribution to the MRDR and your ongoing support of the registry.

We welcome your feedback and suggestions to enhance the usefulness of these reports.
Contact: sphpm-myeloma@monash.edu

Appendix – Second-line chemotherapy regimens

Second-line treatment	Your site		Aus (Excl. [redacted])		New Zealand	
	N	%	N	%	N	%
Rd	34	25	230	18	76	18
DVd	23	17	294	23	3	1
Td	19	14	31	2	44	10
VCd	14	10	80	6	18	4
CTd	14	10	76	6	65	15
IRd	8	6	1	0	1	0
T	3	2	11	1	20	5
R	3	2	24	2	10	2
RP	2	1	1	0	0	0
RCd	2	1	21	2	1	0
VTd	1	1	6	0	76	18
Pod	1	1	6	0	0	0
Vd-PACE	1	1	1	0	1	0
Kd	1	1	70	5	0	0
Vd	1	1	28	2	7	2

Appendix – Chemotherapy regimen codes

Code	Drug
DVCd	Bortezomib, Cyclophosphamide, Daratumamab, Dexamethasone
DVd	Bortezomib, Daratumamab, Dexamethasone
IRd	Dexamethasone, Lenalidomide, Ixazomib
Kd	Carfilzomib, Dexamethasone
Pod	Dexamethasone, Pomalidomide
R	Lenalidomide
RCd	Cyclophosphamide, Dexamethasone, Lenalidomide
RP	Lenalidomide, Prednisolone
Rd	Dexamethasone, Lenalidomide
T	Thalidomide
Td	Dexamethasone, Thalidomide
VCd	Bortezomib, Cyclophosphamide, Dexamethasone
VRd	Bortezomib, Dexamethasone, Lenalidomide
VRdD	Bortezomib, Daratumamab, Dexamethasone, Lenalidomide
VTd	Bortezomib, Dexamethasone, Thalidomide
Vd	Bortezomib, Dexamethasone
Vd-PACE	Bortezomib, Cisplatin, Cyclophosphamide, Dexamethasone, Doxorubicin, Etoposide