



Myelodysplastic Syndromes (MDS) MDSLink Registry: Outcomes update and analysis

Zaira Nosaibah^{1,2}, Cameron Wellard², Sabine Albold², Linda Saravanan³, Selena Squillacioti⁴, Chun Fong⁴, Neil Waters², Erica Wood², Melita Kenealy^{1,2}

¹Cabrini Hospital, ²Monash University, ³Melbourne Pathology, ⁴Austin Hospital, all in Melbourne, Australia

Background

Myelodysplastic syndromes (MDS) are a group of disorders characterised by bone marrow dysfunction and peripheral blood cytopenias. The prevalence and epidemiology of MDS, treatment patterns and resource utilisation within Australia are largely undocumented. Long-term patient follow-up and review of clinical and correlative data outside of clinical trials is valuable in informing optimal treatment strategies for MDS. Clinical registries provide a useful mechanism to collect data on patterns of treatment and variation in survival outcomes. They enable clinicians to benchmark against national and international standards and allow evaluation of the translation of advances in therapy (such as introduction of new targeted therapies) into long-term outcomes outside the setting of clinical trials.

Aim

To update and expand MDSLink registry results with diagnosis, treatment and transfusion data and longitudinal follow up, outcomes and survival.

Method

MDSLink is a multicentre, observational, non-interventional cohort study with over 280 patients with newly diagnosed MDS or AML (<30% blasts on bone marrow biopsy) recruited since 22 August 2018, at 4 Human Research Ethics Committee (HREC) approved Australian sites: Cabrini Hospital, Monash Health and Austin Hospital in Victoria, and Adelaide Hospital in South Australia. This analysis also presents available follow-up data from Cabrini and Austin cohorts.

Results

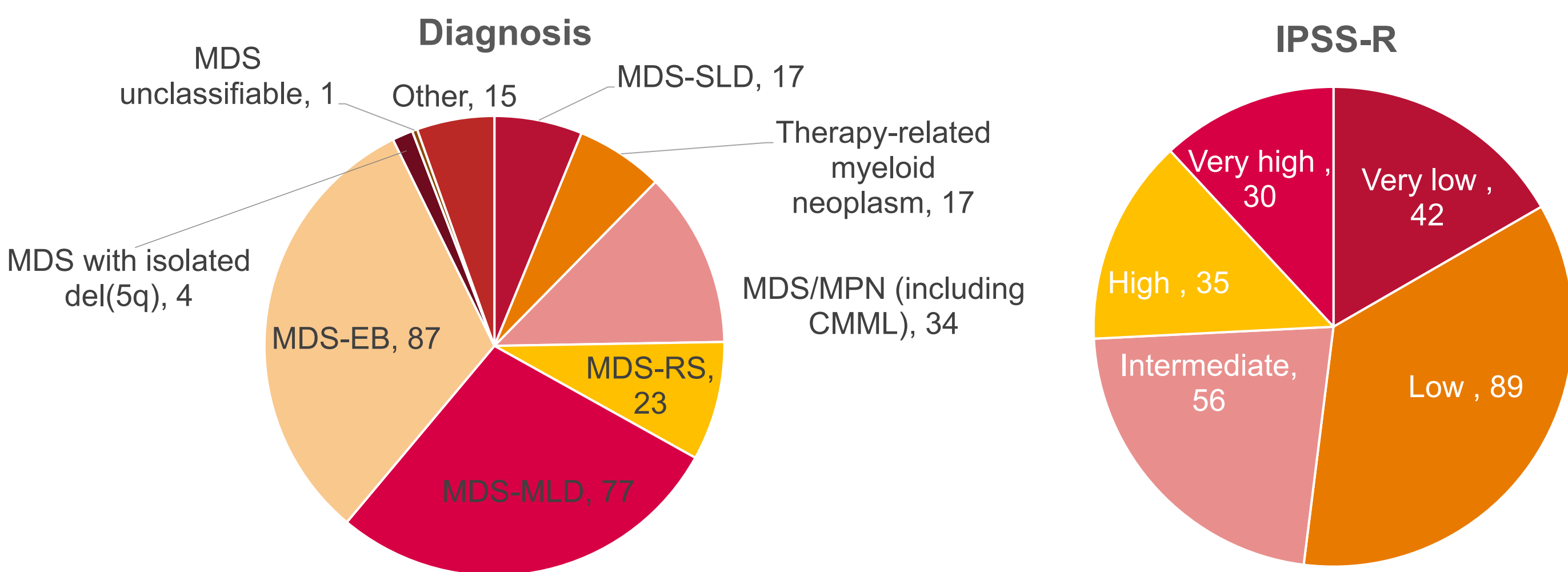
Whole cohort analysis: Baseline and diagnostic data

Demographics

Analysis of 282 patients. Median age 75.3 years (IQR 67.4, 81.7); 36.5% female, 63.5% male.

Diagnosis and IPSS-R prognostic scores

Diagnoses of 275 patients with available data and IPSS-R prognostic scores calculated n=252



Treatment at diagnosis

Of 216 participants with available data regarding supportive care, 86 (39.8%) were receiving red cell transfusion, 31 (14.4%) platelet transfusion, 9 (4.2%) EPO and 9 (4.2%) GCSF.

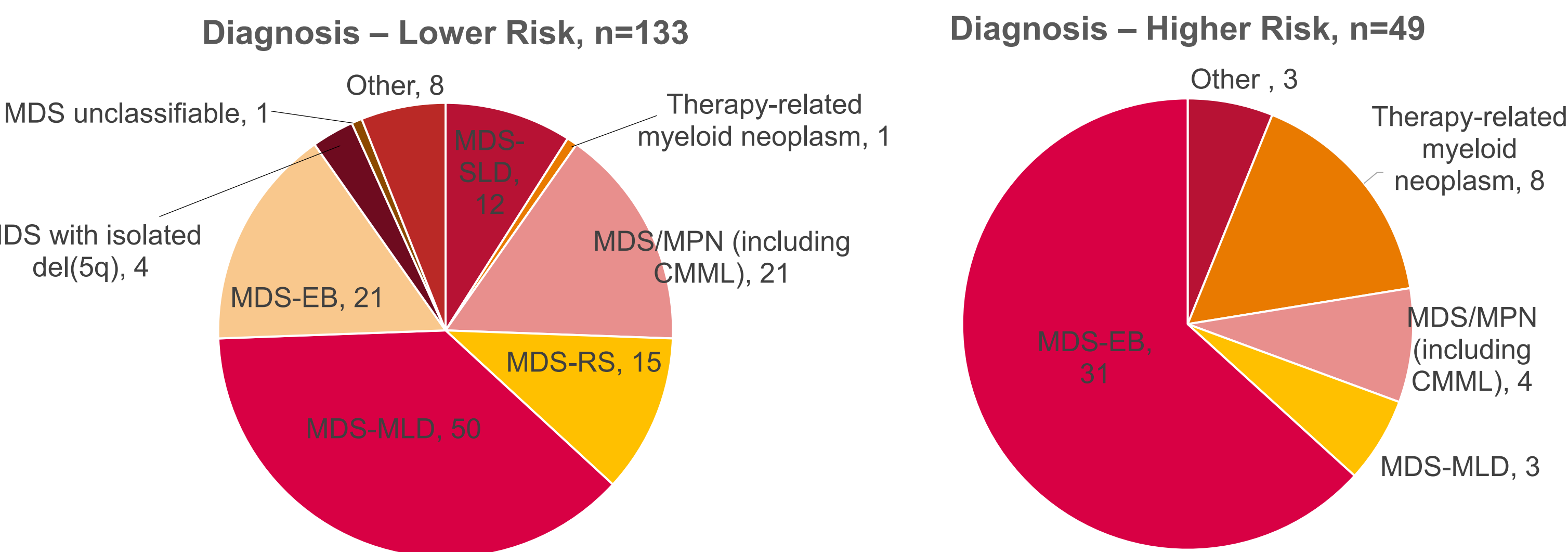
Of 239 with available data regarding active treatment, 52 (21.8%) received azacitidine, 16 (6.7%) chemotherapy, 4 (1.7%) venetoclax, 2 (0.8%) immunosuppressive treatment, 18 (7.5%) clinical trial, 13 (5.4%) other.

Cabrini and Austin subset: Baseline, diagnostic and follow-up data

Demographics

Analysis of 203 patients. Median age 77.2 years (IQR 69.2, 82.0); 64% male, 36% female

MDS Diagnosis



Prognostic scores

IPSS-R calculated in n=182 available data. Cytogenetic category n=185 available data

IPSS-R score	N (%)
≤1.5 : Very low	32 (17.6%)
>1.5 - 3 : Low	64 (35.2%)
>3 - 4.5 : Intermediate	37 (20.3%)
“lower risk”	133 (73.1%)
>4.5 - 6 : High	24 (13.2%)
>6 : Very High	25 (13.7%)
“higher risk”	49 (26.9%)

Cytogenetic category	N (%)
Very good	18 (9.7%)
Good	116 (62.7%)
Intermediate	28 (15.1%)
Poor	10 (5.4%)
Very poor	13 (7.0%)

Treatment at diagnosis and during follow-up

The median follow-up time for the Cabrini/Austin subset was 26 months (0-145 months).

Treatment	Lower risk n (%)	Higher risk n (%)	Lower risk n (%)	Higher risk n (%)
	Supportive – baseline		Supportive – any time in follow-up	
Data available	131	48	130	47
RBC	35 (26.7%)	32 (66.7%)	63 (48.5%)	38 (80.9%)
Platelets	9 (6.9%)	13 (27.1%)	23 (17.7%)	19 (40.4%)
GCSF	5 (3.8%)	3 (6.3%)	18 (13.8%)	9 (19.1%)
EPO	9 (6.9%)	0 (0%)	26 (20%)	1 (2.1%)
	Active – baseline		Active – any time in follow-up	
Data available	131	48	130	48
Azacitidine	6 (4.6%)	20 (41.7%)	27 (20.8%)	25 (52.1%)
Chemotherapy	2 (1.5%)	4 (8.3%)	13 (10.0%)	9 (18.8%)
Venetoclax	1 (0.8%)	3 (6.2%)	14 (10.8%)	7 (14.6%)
Clinical trials	4 (3.1%)	5 (10.4%)	10 (7.7%)	12 (25.0%)
Other	3 (2.3%)	7 (14.6%)	22 (16.9%)	15 (31.2%)

At any time during follow-up, only 2 patients received lenalidomide and 4 patients received immunosuppressive treatment from only the lower-risk group.

Transfusion dependence

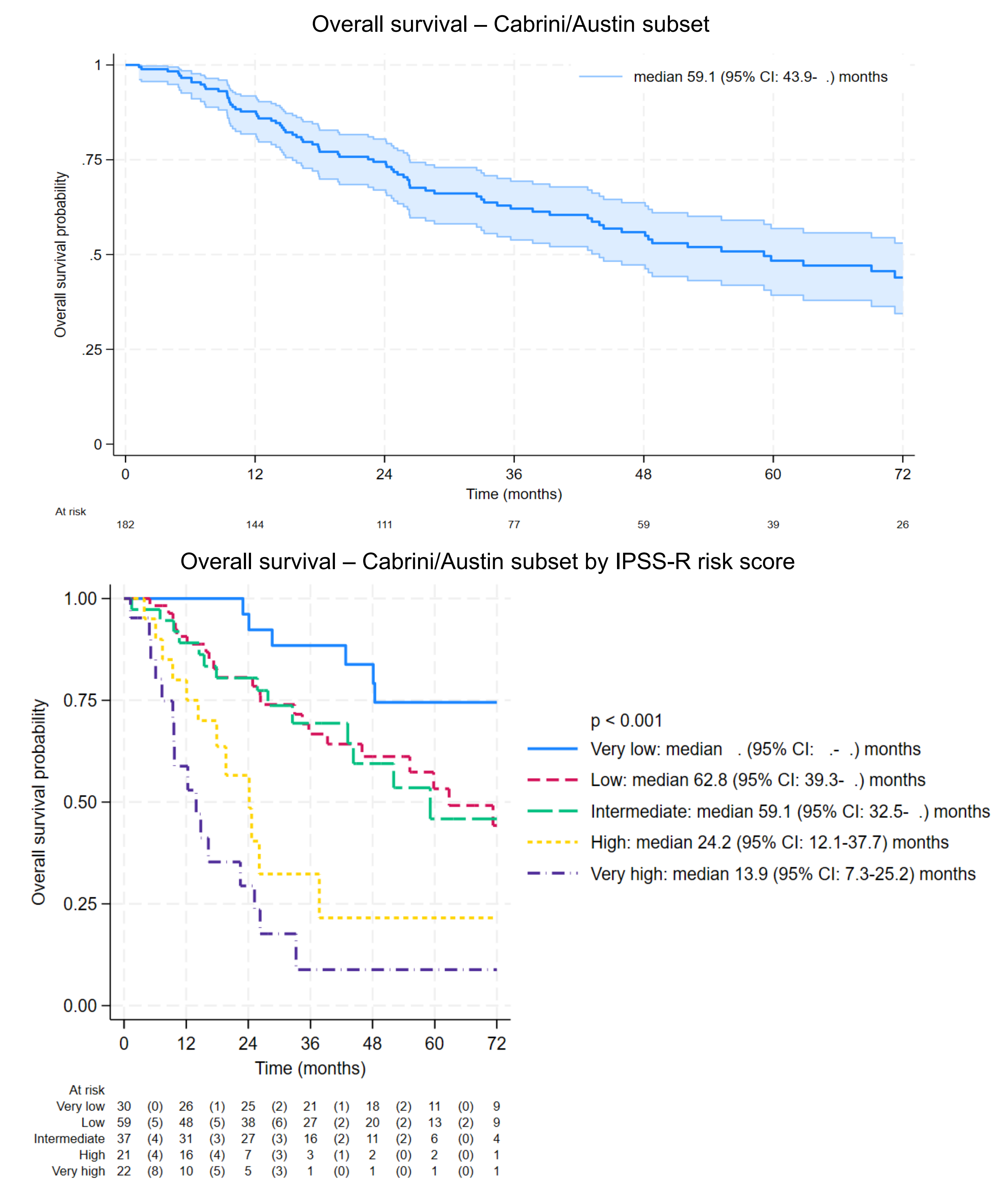
Red blood cell transfusion dependence was classified as at least 2 units in the preceding 8 weeks, and platelet transfusion as 1 unit in the preceding 8 weeks.

Data for transfusion dependence was available for n=111 lower-risk patients and n=34 higher-risk.

Transfusion Dependence	Lower risk n (%)	Higher risk n (%)	Lower risk n (%)	Higher risk n (%)
	At diagnosis		At last known follow-up	
RBC	27 (24.3%)	18 (52.9%)	46 (41.4%)	19 (55.9%)
Platelets	5 (4.5%)	10 (29.4%)	18 (16.2%)	13 (38.2%)

Additionally, at any time during follow-up, iron chelation was required for 13/130 lower-risk patients (10%) and 1/47 higher-risk patients (2.1%).

Overall survival – consistent with literature for OS and according to subtype



Conclusion

MDSlink provides an important resource for describing a cohort of MDS patients not previously captured in Australia. Follow-up data provides a foundation for optimising patient management and informing future clinical decision-making, including resource allocation. Analysis of lower and higher risk groups allows visualisation of resource distribution. Molecular data has not been incorporated at this point; however, will be a focus of further analysis

Acknowledgements

We thank patients and staff at Austin Health, Cabrini Hospital, Monash Health, and Royal Adelaide Hospital for participating in MDSlink.

