

SALSA Site Report (All Sites)

PCTG

25 November 2019

Contents

1	SALSA Recruitment	2
1.1	SALSA Recruitment by Clinical Site	2
1.2	Research Participant Type	3
1.3	Rate of Recruitment Across All Clinical Sites	3
2	Symptom Onset and Diagnosis	4
2.1	MND Cases Age at Symptom Onset	4
2.2	MND Cases Age at Diagnosis	4
2.3	Time from Symptom Onset to Diagnosis	5
2.4	Region of Onset	5
2.5	Tests Used to Inform Diagnoses	6
3	MND Type	7
3.1	MND Type at Baseline (Primary Visit)	7
3.2	Current MND Type (Last Clinical Visit)	7
4	ALSFRS Scores	8
4.1	MND Cases ALSFRS Score	8
4.2	MND Cases ALSFRS Scores over Time	8
5	Other Cohort Information	9
5.1	Family History	9
5.2	Gender	9
5.3	Education	10
5.4	Occupation	10
6	Adaptive Device and Health Resource Use	11
6.1	Adaptive Device Use	11
6.2	Health Resources Utilised	13
7	Biological Collections	15
7.1	Rate of Biological Sample Collections Across All Clinical Sites	15
7.2	Biological Collections per Site	15
7.3	Biological Collections from Date of Diagnosis	16
7.4	Biological Collections from Date of Onset	16

This report details clinical data and biological samples collected from individuals participating in the SALSA project between 01 April 2016 and 31 May 2019. The report has been run across all participants with a current consent. The following plots include individuals under these conditions:

- Where information is unknown, it has been plotted as ‘Unknown’
- Included individuals were recruited for SALSA between 01 April 2016 and 31 May 2019
- Included cases had one or more clinical data collections
- Included carers, controls and asymptomatics had one or more biological collections
- Clinical data plots include cases only
- MQC recruitment and biological collection counts were provided by Sarah Furlong via email on 6 June 2019
- MQC subsequent visits have not been included

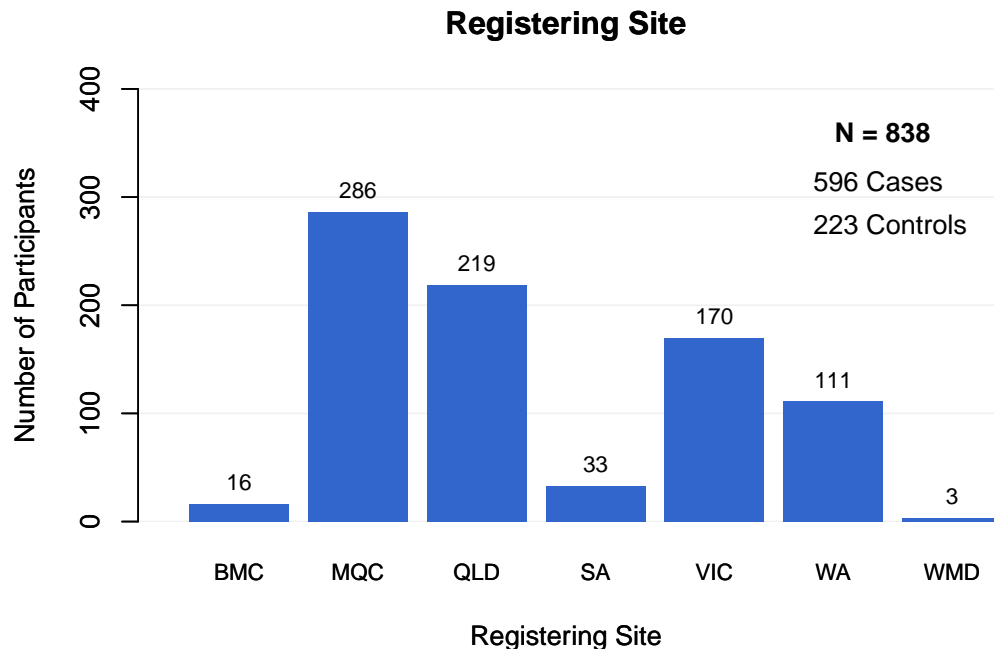
Cohort Overview:

	SALSA Cohort excluding MQC		SALSA Cohort	
	Cases	All	Cases	All
Total	464	552	596	838
Unique Individuals with Clinical Visits	445	445	548	548
Total Clinical Visits	1174	1174	1277	1277
Unique Individuals with Biological Collections	434	522	566	808
Total Biological Collections	1039	1133	1467	1863

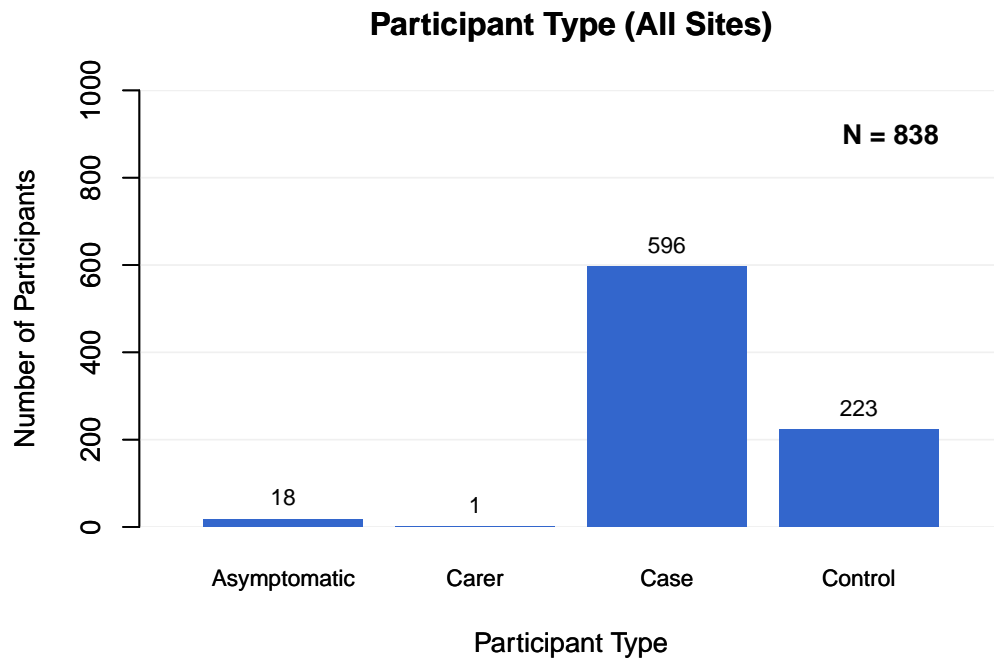
1 SALSA Recruitment

1.1 SALSA Recruitment by Clinical Site

Research participants include MND cases and controls.

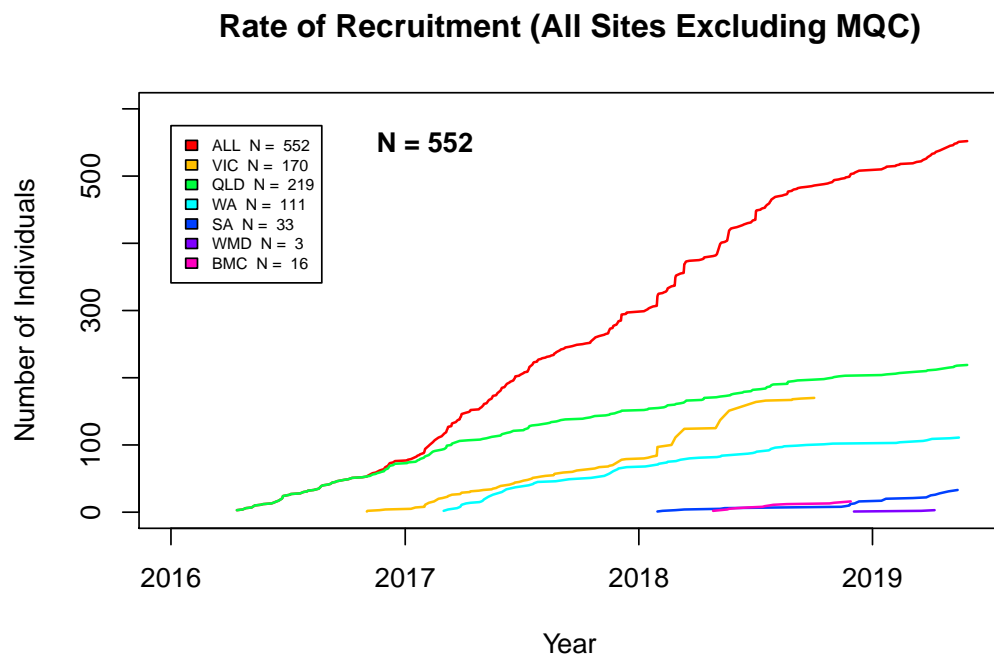


1.2 Research Participant Type



1.3 Rate of Recruitment Across All Clinical Sites

This plot includes biological collections from cases, controls and asymptomatics.

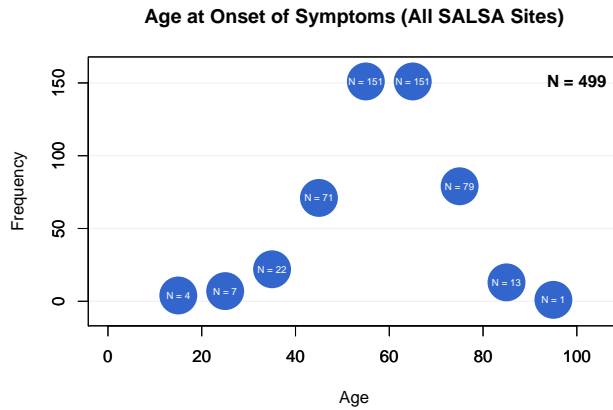


2 Symptom Onset and Diagnosis

2.1 MND Cases Age at Symptom Onset

There are 548 clinical visits across the SALSA cohort. 499 have been included in the following plot.

- SALSA cohort unknown N = 49

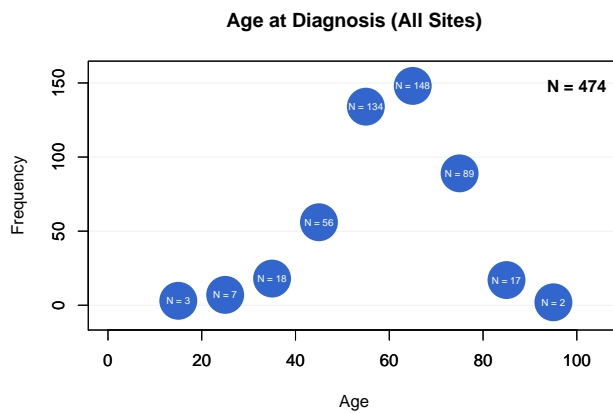


Age Group	% Frequency	% Family History
11-20yrs	1	0.0
21-30yrs	1	14.3
31-40yrs	4	9.1
41-50yrs	14	18.3
51-60yrs	30	13.2
61-70yrs	30	11.9
71-80yrs	16	6.3
81-90yrs	3	15.4
91-100yrs	0	0.0

2.2 MND Cases Age at Diagnosis

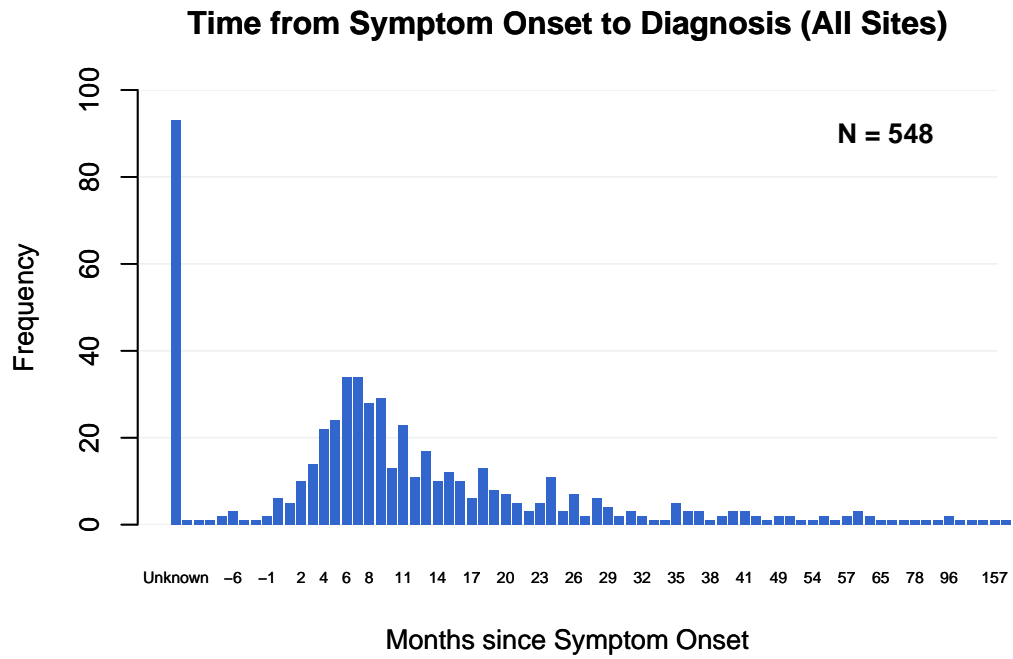
There are 548 clinical visits across the SALSA cohort. 474 have been included in the following plot.

- SALSA cohort unknown N = 74

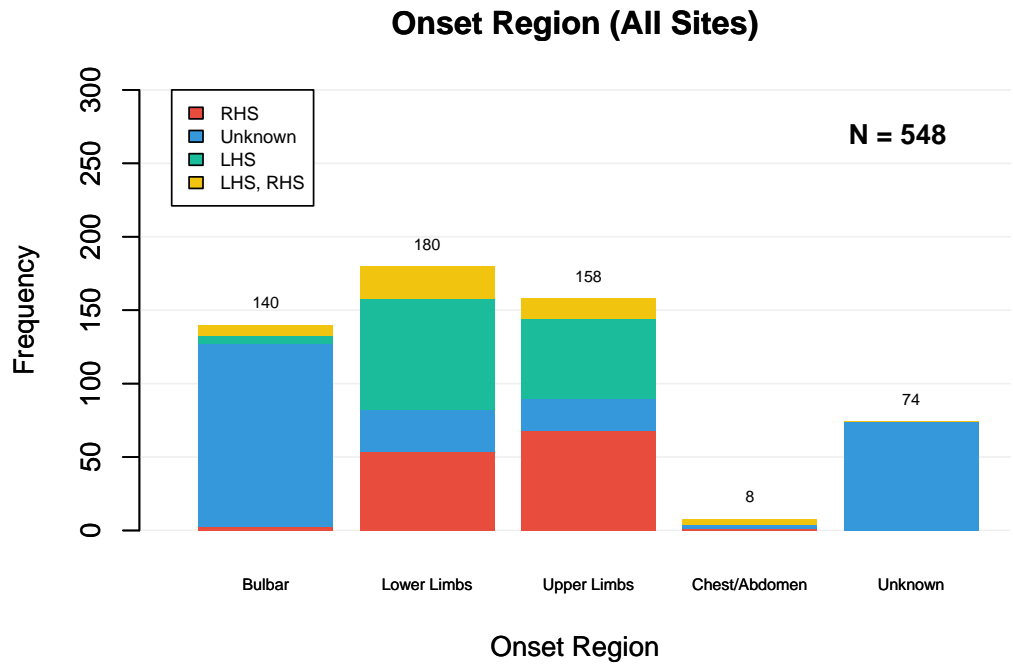


Age Group	% Frequency	% Family History
11-20yrs	0.6	0.0
21-30yrs	1.5	14.3
31-40yrs	3.8	11.1
41-50yrs	11.8	14.3
51-60yrs	28.3	15.7
61-70yrs	31.2	10.1
71-80yrs	18.8	5.6
81-90yrs	3.6	11.8
91-100yrs	0.4	0.0

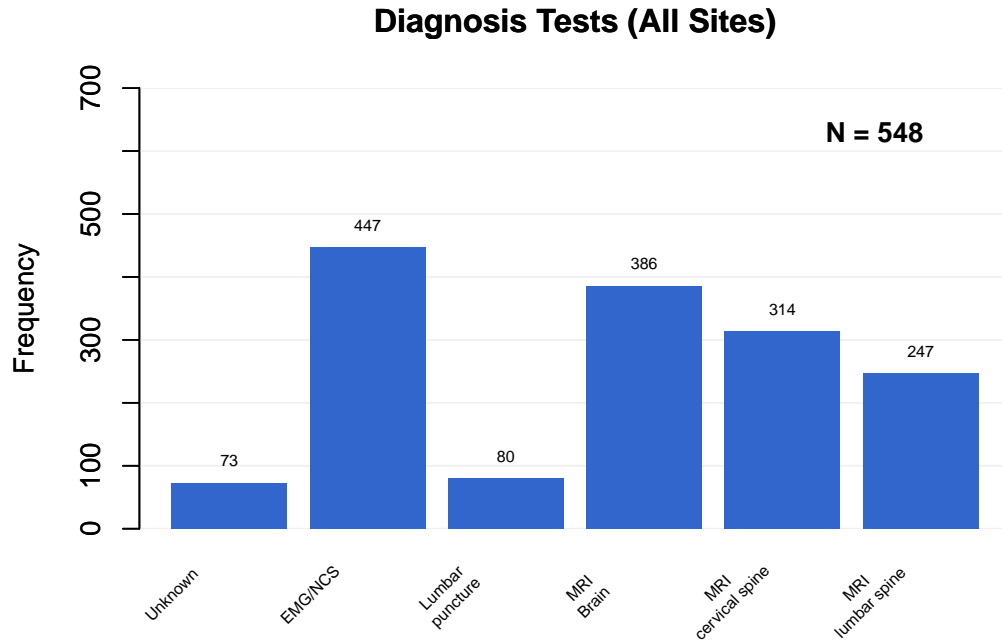
2.3 Time from Symptom Onset to Diagnosis



2.4 Region of Onset

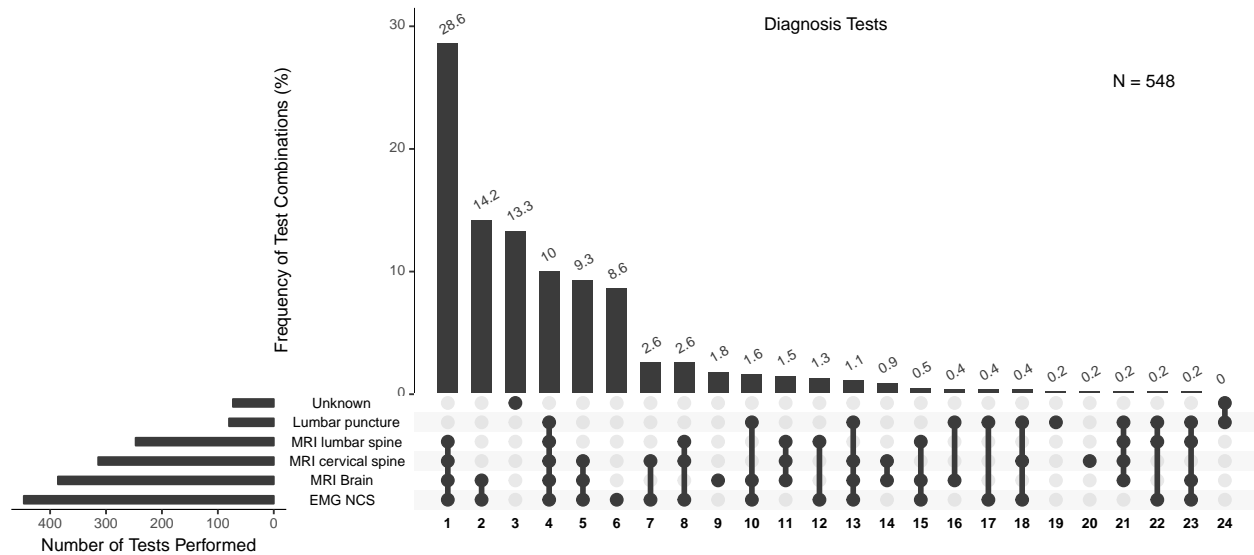


2.5 Tests Used to Inform Diagnoses



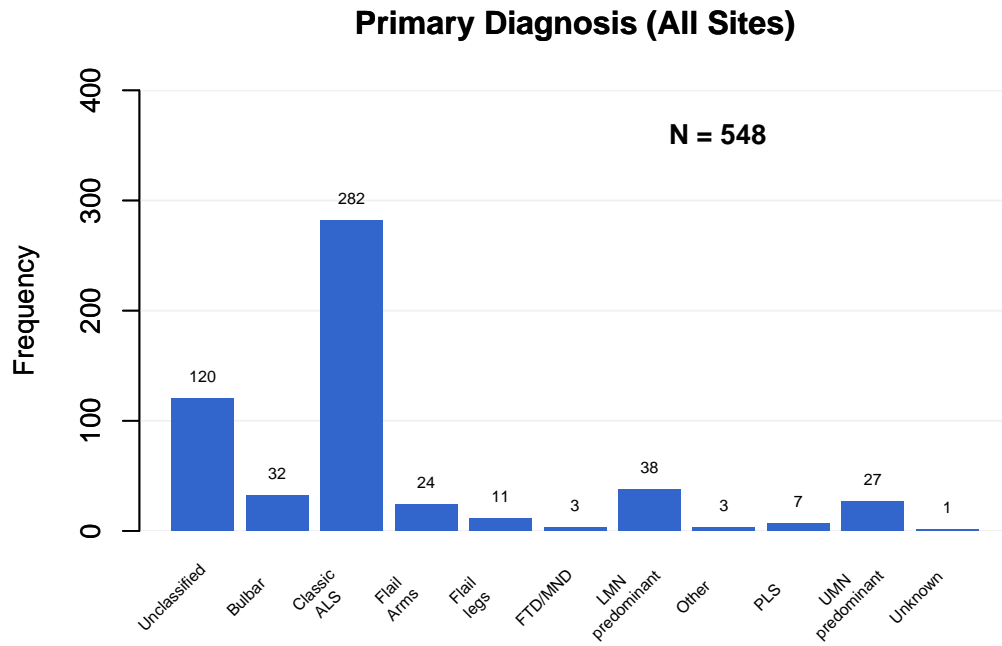
The most common combination of tests ordered is MRI Brain, MRI cervical spine, MRI lumbar spine and EMG/NCS at 28.6% closely followed by 14.2% for MRI Brain and EMG/NCS.

UpSetR plot:

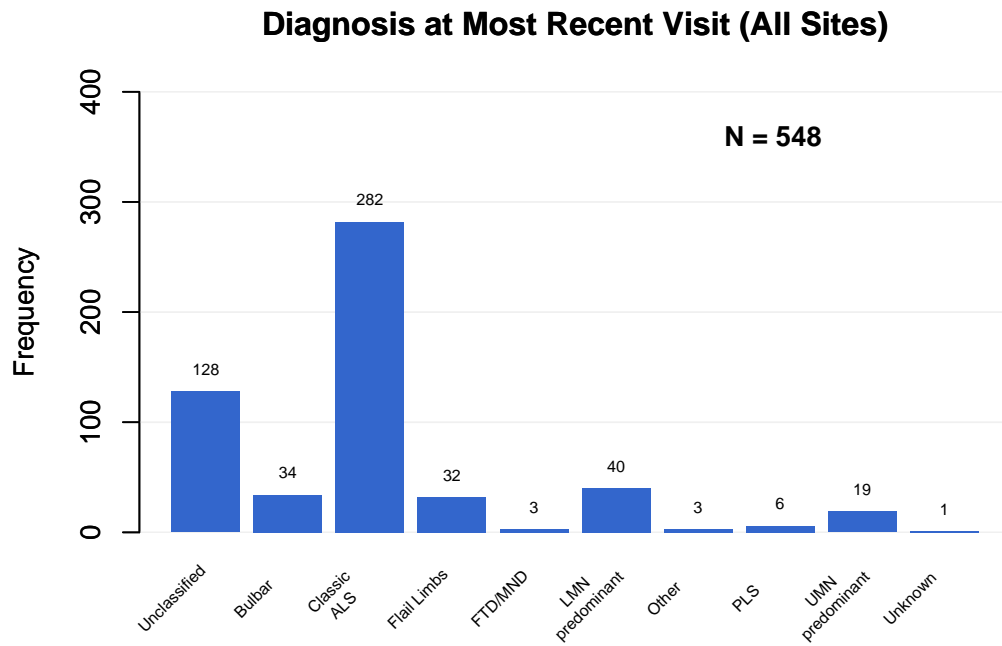


3 MND Type

3.1 MND Type at Baseline (Primary Visit)



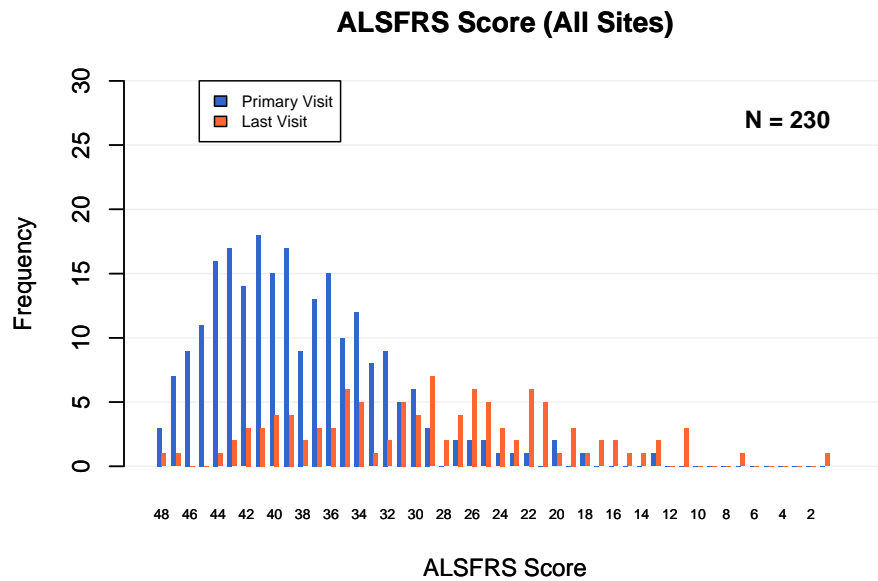
3.2 Current MND Type (Last Clinical Visit)



4 ALSFRS Scores

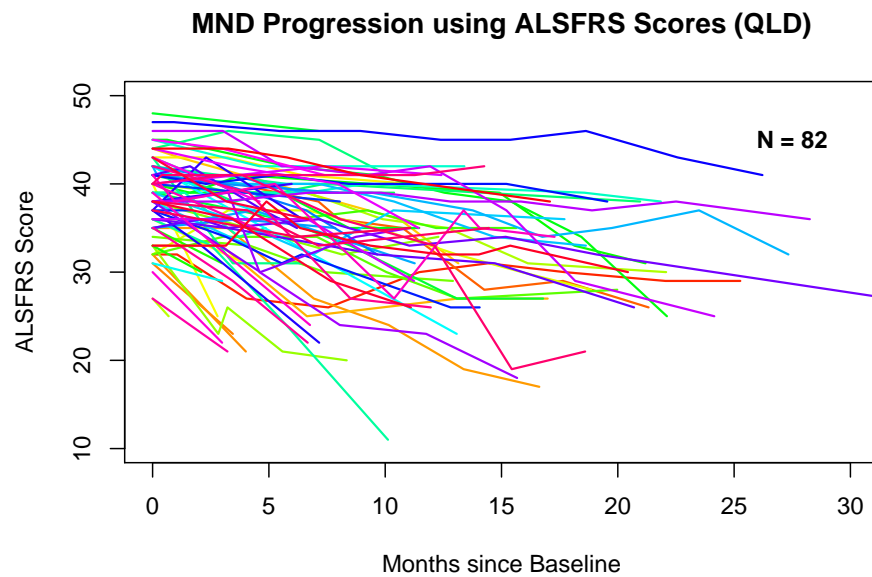
4.1 MND Cases ALSFRS Score

This plot shows the distribution of ALSFRS scores at baseline (within six months of diagnosis) compared to scores recorded at individual's last clinical appointment. The same group of individuals have been included for both timepoints.



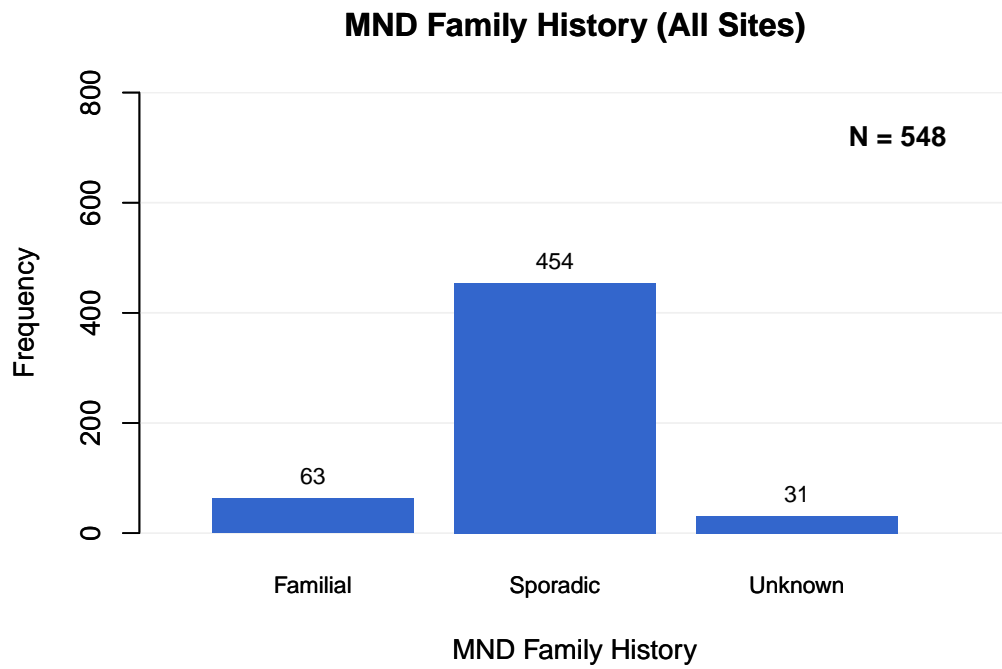
4.2 MND Cases ALSFRS Scores over Time

This plot only includes those cases where there is two or more clinical visits.

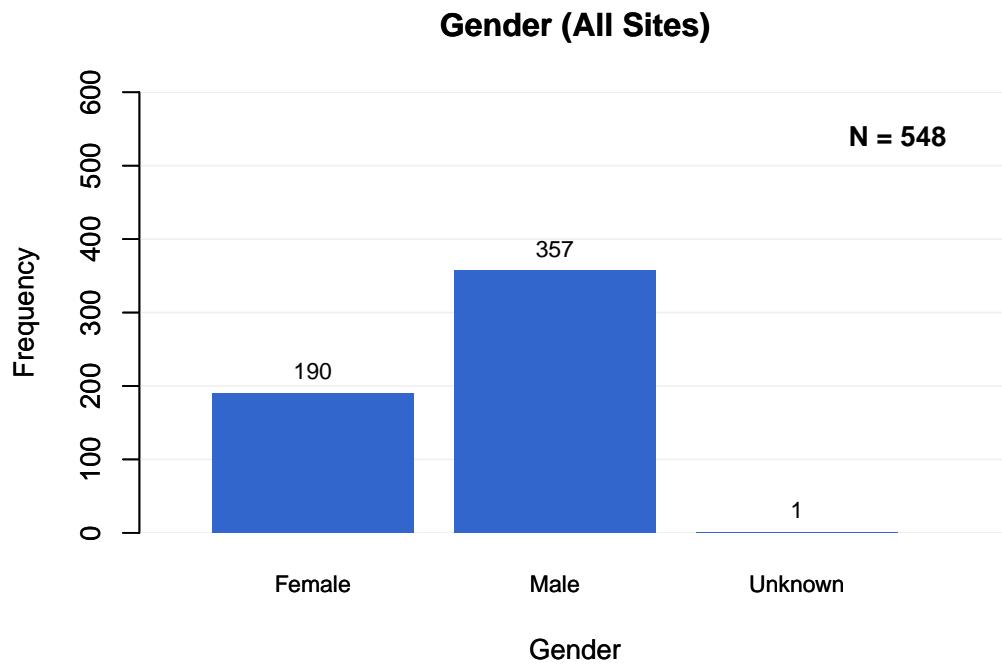


5 Other Cohort Information

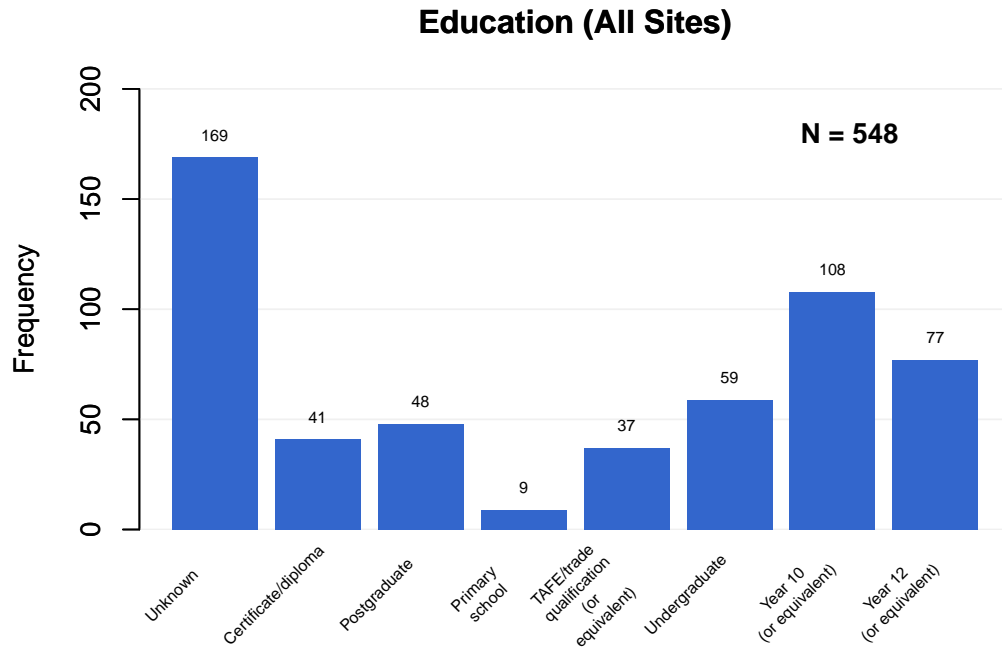
5.1 Family History



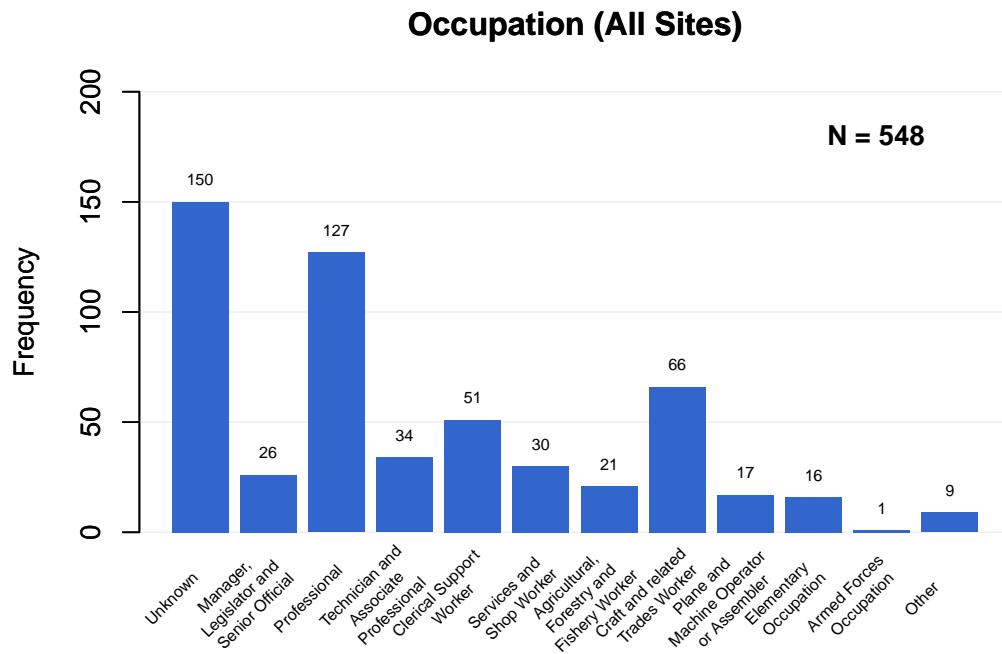
5.2 Gender



5.3 Education



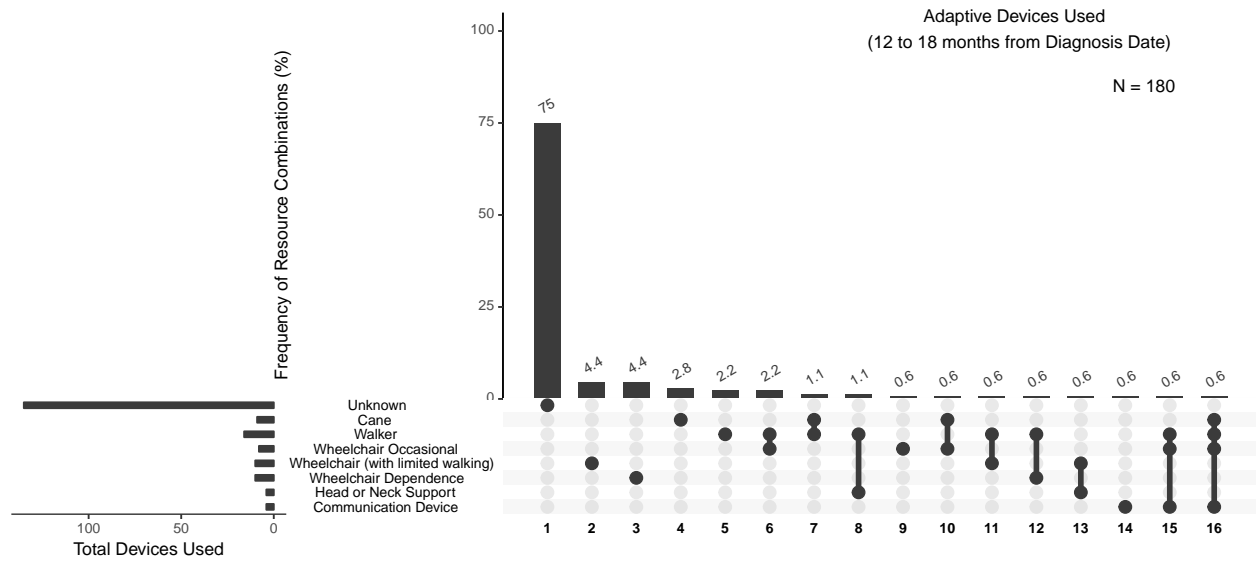
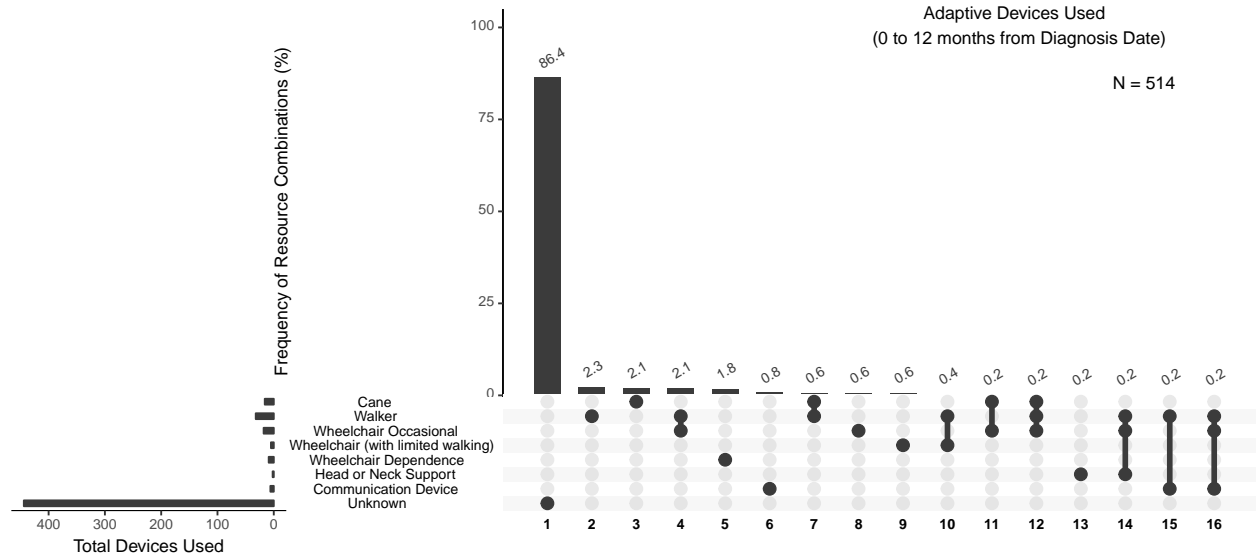
5.4 Occupation

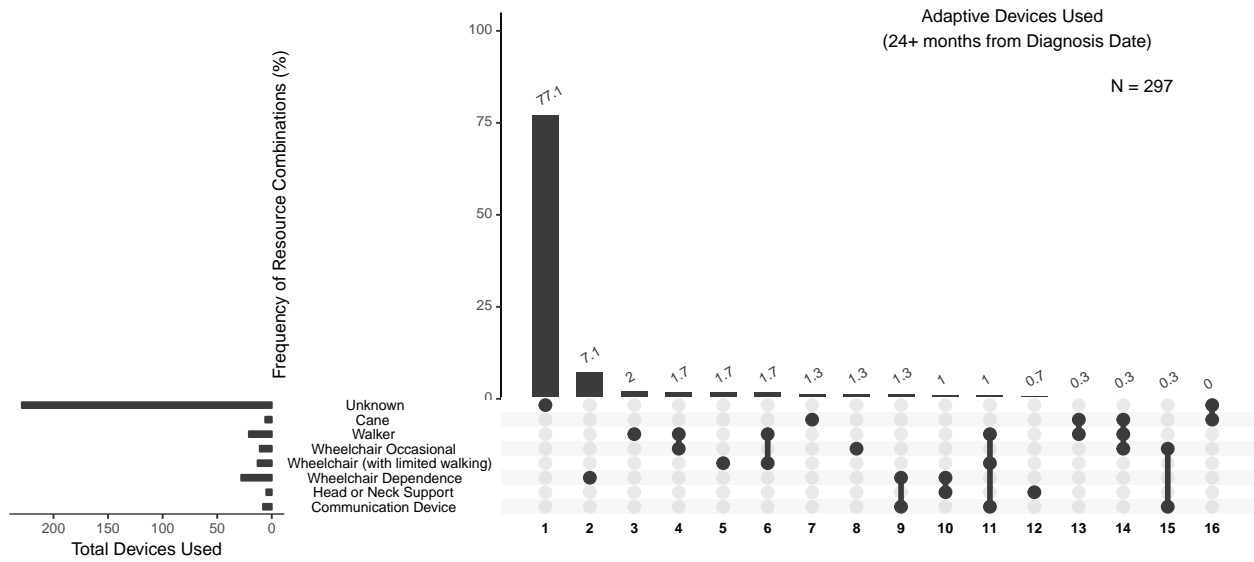
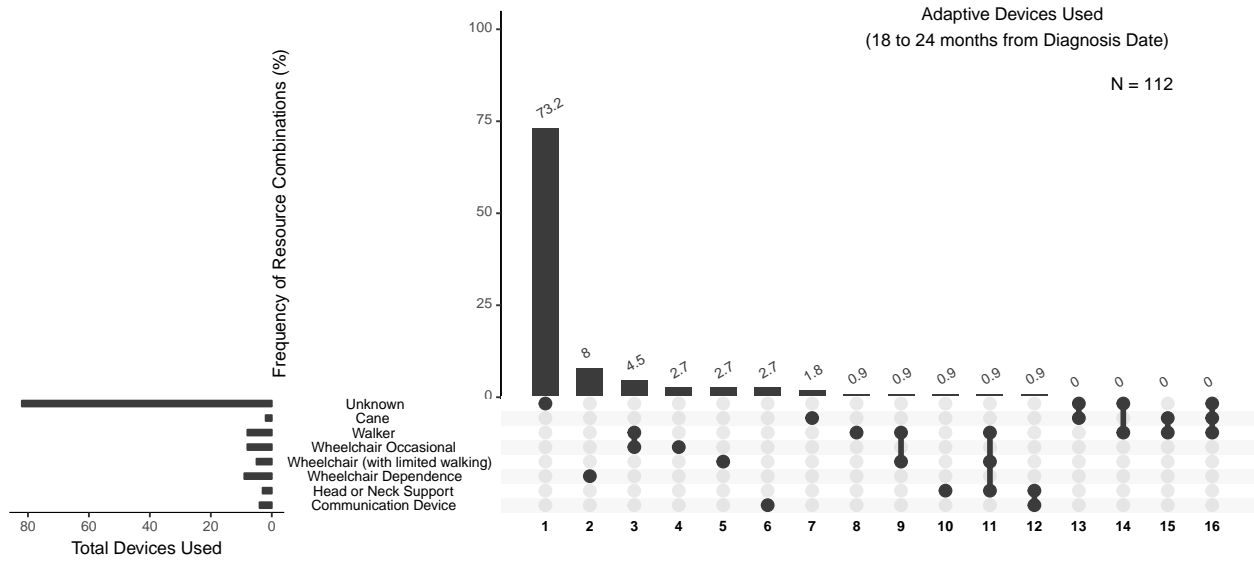


6 Adaptive Device and Health Resource Use

6.1 Adaptive Device Use

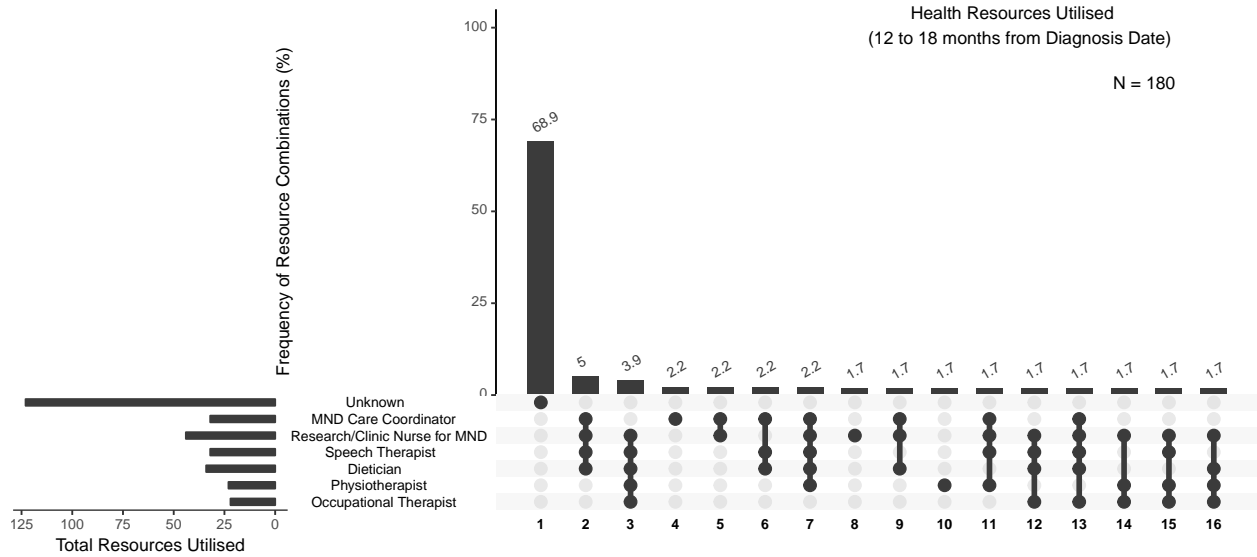
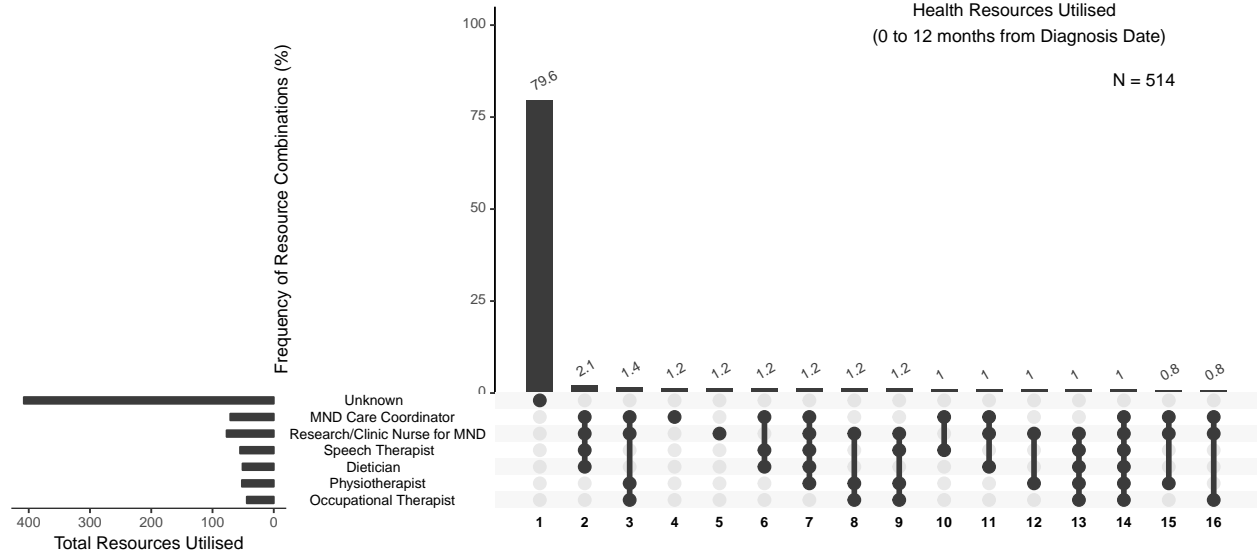
The following plots are across all SALSA sites.

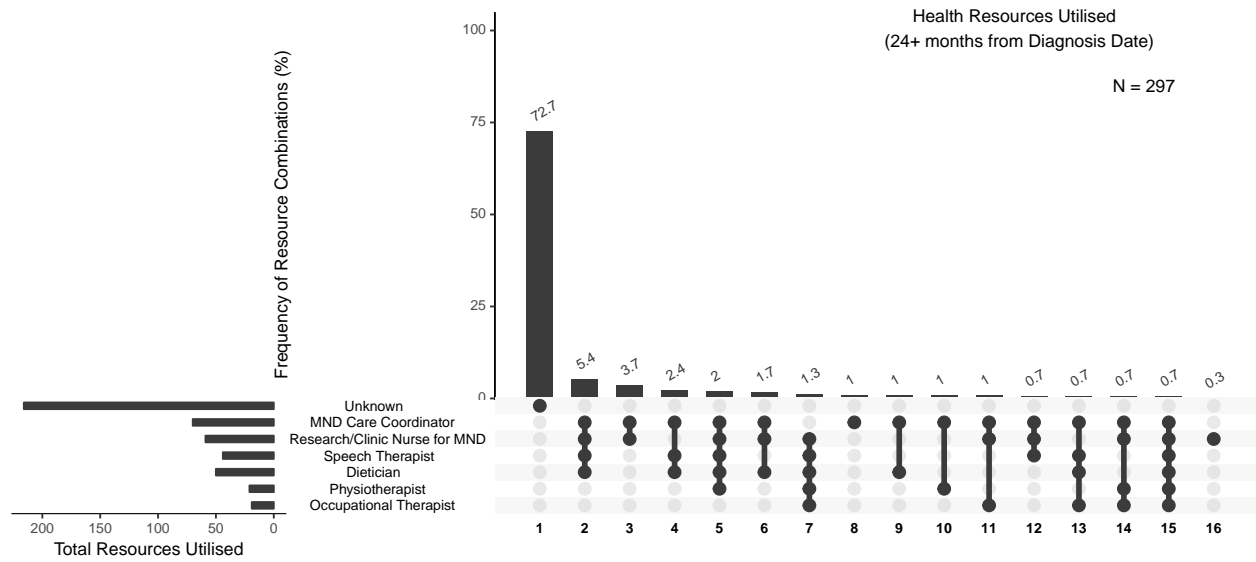
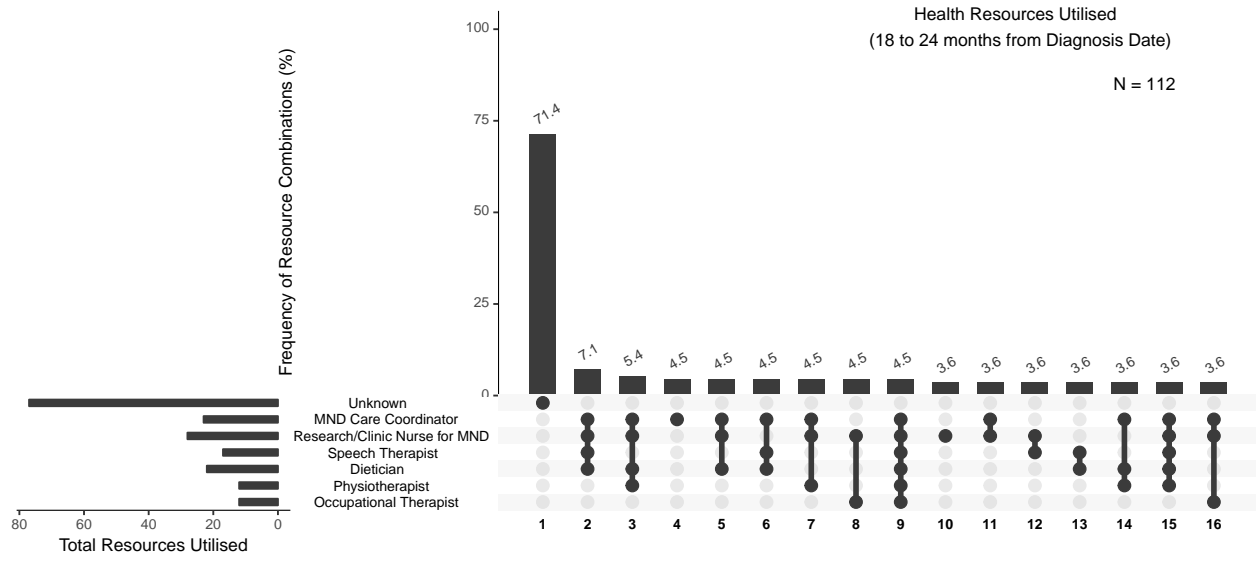




6.2 Health Resources Utilised

The following plots are across all SALSA sites.



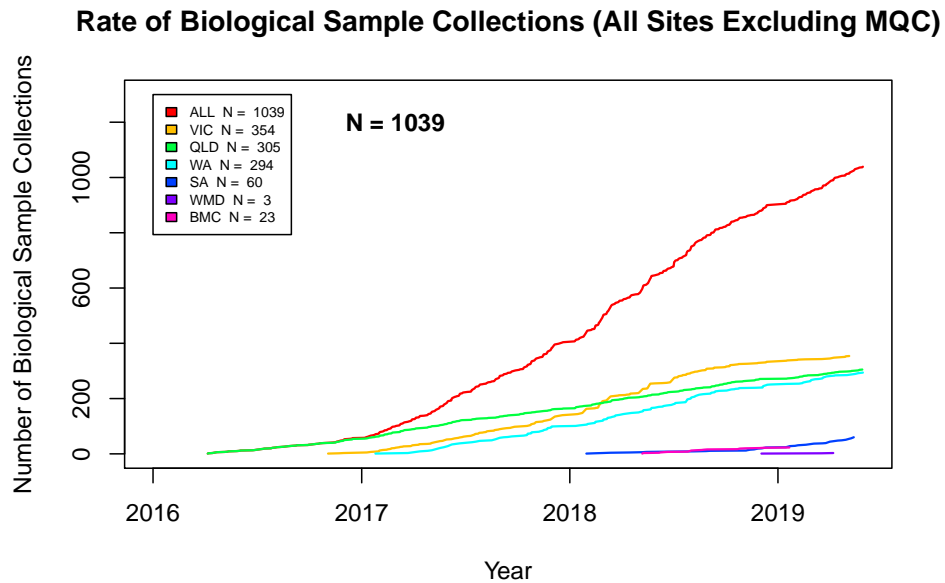


7 Biological Collections

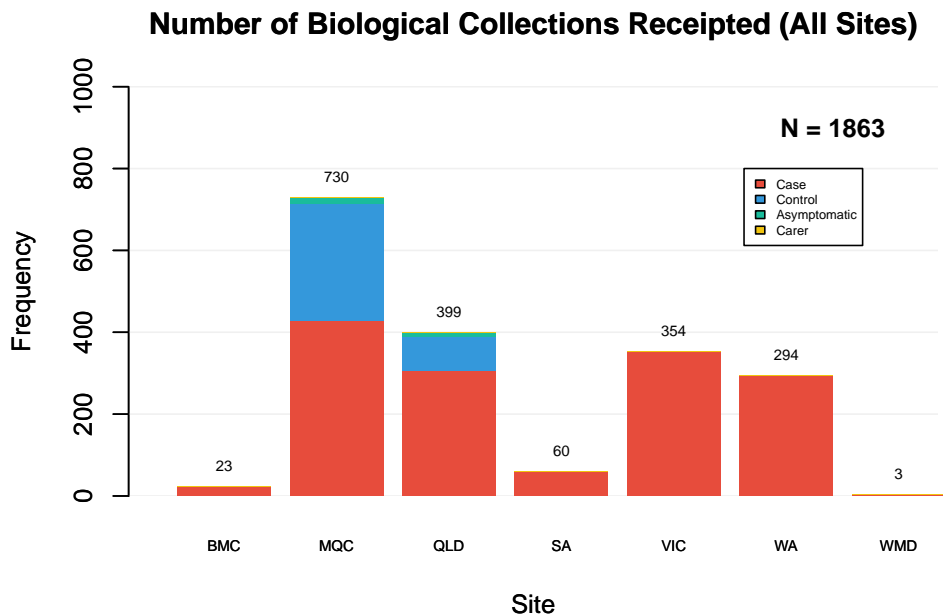
Biological samples are collected every three months from each individual as long as they are able. 1863 samples have been collected for 808 individuals.

7.1 Rate of Biological Sample Collections Across All Clinical Sites

This plot includes cases only.



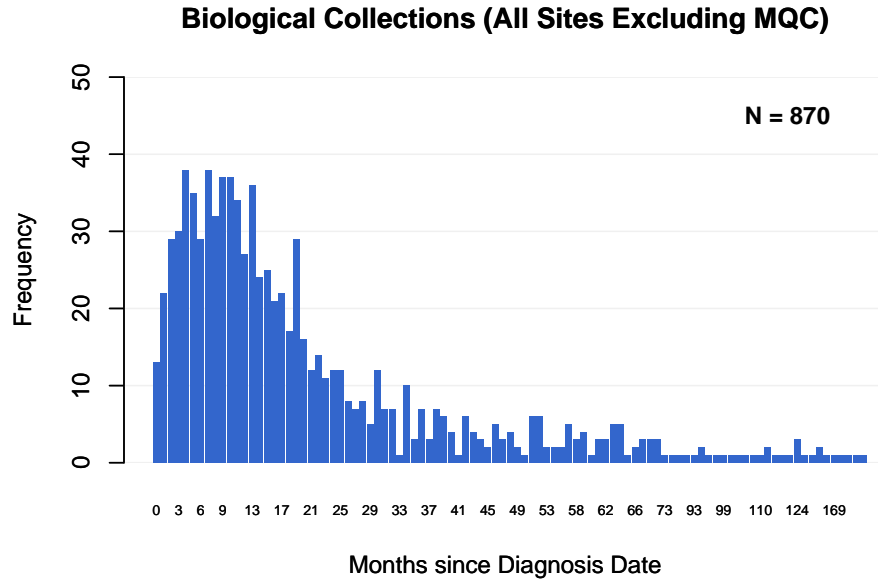
7.2 Biological Collections per Site



7.3 Biological Collections from Date of Diagnosis

There are 1039 biological collections for cases across the SALSA cohort. 870 respectively have been included in the following plot.

- SALSA cohort unknown N = 169



7.4 Biological Collections from Date of Onset

There are 1039 biological collections for cases across the SALSA cohort. 898 have been included in the following plots.

- SALSA cohort unknown N = 141

