

Women's and Children  
Paediatric Neurosciences  
Inherited White Matters Disorders Diagnostic and Management Service (IWMD) (All Ages)

1662(HSS)

Code	Metric	Numerator	Denominator	Period Type	Frequency	Data Source Numerator	Data Source Denominator	Target	Notes	Q1	Q2	Q3	Q4
1662/101	Proportion of patients receiving an MDT discussion	Total number of patients receiving an MDT discussion in the period	Total number of patients referred to IWMD service in the period	Annual	Annual	IWMD Registry	IWMD Registry			N/A	N/A	N/A	Apr-22 - Mar-23
1662/102	Proportion of level 2 patients who receive next generation sequencing molecular testing	Total number of level 2 patients who receive next generation sequencing molecular testing in the period	Total number of patients referred to IWMD service in the period	Annual	Annual	IWMD Registry	IWMD Registry			N/A	N/A	N/A	Apr-22 - Mar-23
1662/103	Proportion of level 3 clinics where key MDT staff groups as outlined in the service specification are represented and meet with the patient	Total number of level 3 clinics where key MDT staff groups as outlined in the service specification are represented and meet with the patient in the period	Total number of level 3 clinics held in the period	Annual	Annual	IWMD Registry	IWMD Registry			N/A	N/A	N/A	Apr-22 - Mar-23
1662/104	Proportion of parents of a paediatric IWMD patient who receive genetic counselling	Total number of parents of a paediatric IWMD patient who receive genetic counselling in the period	Total number of IWMD parents of paediatric IWMD patients diagnosed in the period	Annual	Annual	IWMD Registry	IWMD Registry			N/A	N/A	N/A	Apr-22 - Mar-23
1662/105	Proportion of adult IWMD patients who receive genetic counselling	Total number of adult IWMD patients who receive genetic counselling in the period	Total number of adult IWMD patients diagnosed in the period	Annual	Annual	IWMD Registry	IWMD Registry			N/A	N/A	N/A	Apr-22 - Mar-23
1662/106	Proportion of cases in which a treatment plan has been agreed	Total number of cases in which a treatment plan has been agreed in the period	Total number of IWMD patients diagnosed in the period	Annual	Annual	IWMD Registry	IWMD Registry		To include all definitive, supportive or symptomatic treatment plans	N/A	N/A	N/A	Apr-22 - Mar-23
1662/107	Proportion of patients recruited to a clinical trial	Total number of patients recruited to a clinical trial in the period	Total number of IWMD patients diagnosed in the period	Annual	Annual	IWMD Registry	IWMD Registry			N/A	N/A	N/A	Apr-22 - Mar-23