

## Section 12

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At the end of each PEEK study, CCDD identifies three key areas that, if improved, would significantly increase the quality of life and/or the ability for individuals to better manage their own health.

In relation to this community, these three areas are:

**1. Information:** Throughout the study, participants noted the difficulties in finding local, disease-specific information. This patient population would benefit from an Australian website with transparent and forthcoming information about what NMOSD is, as well as current and emerging treatments. This may be complemented by an annual or biennial conference updating the community on current research and treatments.

**2. Health system navigation:** Once diagnosed with NMOSD, there is complex health system that needs to be navigated to ensure patients are accessing allied health and supportive care. This patient population would benefit from the development of a 'Health System Navigation' kit, so that they can anticipate the services that they may need in the future and how to access them.

**3. Symptom tracking and monitoring:** A recurring theme within the study was the importance of avoiding relapse and maintaining current health and independence. This patient population would benefit from the development of bespoke symptom tracking tools so that they can monitor their ability to function over time and recognise changes so that they can access timely or early medical or therapeutic interventions.

## 2020 NMOSD

Data collected in this PEEK study also provides a basis on which future interventions and public health initiatives can be based. Some of the 2020 metrics that the sector can work together to improve upon are provided in Table 12.1

**Table 12.1 NMOSD 2020 Metrics**

Measure	Detail	Mean	Median
Baseline health (SF36)	Physical functioning	53.61*	62.50
	Role functioning/physical	30.56	0.00
	Role functioning/emotional	31.48	0.00
	Energy/fatigue	28.33*	27.50
	Emotional well-being	57.56*	62.00
	Social functioning	47.92*	50.00
	Pain	43.06*	45.00
	General health	32.78*	32.50
	Health change	43.06	37.50
Knowledge of condition and treatments (Partners in Health)	Knowledge	23.00*	22.00
	Coping	11.50*	11.50
	Recognition and management of symptoms	17.72*	19.00
	Adherence to treatment	12.89*	12.50
	Total score	65.11*	62.50
Care coordination scale	Communication	30.94	29.50
	Navigation	20.56*	21.50
	Total score	51.50*	52.00
	Care coordination global measure	5.67*	6.00
	Quality of care global measure	6.00	6.00
Fear of progression	Total Score	41.33*	41.50
		Percent	
Accessed My Health Record	-	50.00%	-
Participants that had discussions about biomarkers/genetic tests	-	27.78%	-