

## Section 12

### Next steps

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At the end of each PEEK study, CCDR 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

Information that provides families with more current and specific details about diagnosis, treatment, allied health management, prognosis, practical support and importantly, peer support. This may also include information that patients/families can take to clinicians to educate them on the condition, and to give to families and friends to help them understand the condition. Treatment information and decision tools should empower families to weigh up benefits, risks, side effects, quality of life, and to be informed about costs.

### 2. Care coordination

Pre and post diagnosis there is a complex health system that needs to be navigated to ensure patients are accessing allied health and supportive care. This patient population would benefit from health system navigation services to support timely diagnosis to and to provide holistic management of a broad range of rare diseases to patient and their families and ensure continuity of care across health and social services.

### 3. Support

Rare diseases have a negative impact on quality of life, mental health and relationships often due to the emotional and mental health strain. This group could benefit from emotional and mental health support both for patients, families and carers. Respite care will be an important aspect of this to allow carers time to access these services.

## 2024 PEEK study in Rare and Genetic Conditions

Data collected in this PEEK study also provides a basis on which future interventions and public health initiatives can be based. Some of the 2023 metrics that the sector can work together to improve upon are provided in Table 12.1

**Table 12.1 Rare diseases 2024 Metrics**

Measure	Detail	Mean	Median
Baseline health (SF36)	Physical functioning	54.32	55.00
	Role functioning/physical	37.24	25.00
	Role functioning/emotional	51.22	66.67
	Energy/fatigue	33.69	30.00
	Emotional well-being	64.09	68.00
	Social functioning	53.08	50.00
	Pain	55.69	55.00
	General health	41.64	40.00
	Health change	44.76	50.00
Knowledge of condition and treatments (Partners in Health)	Knowledge	24.07	26.00
	Coping	14.35	14.00
	Recognition and management of symptoms	18.89	19.00
	Adherence to treatment	13.12	14.00
	Total score	70.44	72.00
Care coordination scale	Communication	35.55	36.00
	Navigation	22.96	23.00
	Total score	58.51*	60.00
	Care coordination global measure	5.79	6.00
	Quality of care global measure	6.59	7.00
Fear of progression	Total Score	37.09*	37.00
		<b>Percent</b>	
Accessed My Health Record	-	39.31	-
Participants that had discussions about biomarkers/genetic tests	-	33.44	-