

# **Section 12 Next steps**

## Next steps

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 the mitochondrial disease community, these three areas are:

1. Mechanisms to support health professional education, including those that support patients in explaining their condition to new health professionals that they may encounter
2. Case management services to provide holistic management of mitochondrial disease to patient and their families and ensure continuity of care across health services
3. Information that empowers patients, particularly at diagnosis; and ensure that all information is available in formats that are appropriate to those with visual and hearing impairments

## 2018 Mitochondrial disease metrics

Data collected in this PEEK study also provides a basis on which future interventions and public health initiatives can be based. Some of the 2018 mitochondrial disease metrics that the sector can work together to improve upon are provided in Table 12.1

Table 12.1: Mitochondrial disease 2018 Metrics

Area of evaluation	2018 data	
<b>Baseline health</b>	<b>Mean</b>	<b>Median</b>
<b>Physical functioning</b>	<b>32.50</b>	<b>43.75</b>
Role functioning/physical	12.50	0.00
<b>Role functioning/emotional</b>	<b>43.33</b>	<b>33.33</b>
Energy/fatigue	22.50*	25.00
<b>Emotional well-being</b>	<b>64.00</b>	<b>68.00</b>
Social functioning	39.75	37.50
<b>Pain</b>	<b>46.90</b>	<b>45.00</b>
General health	28.00	25.00
<b>Health change</b>	<b>35.50</b>	<b>25.00</b>
<b>Percentage of participants that have accessed My Health Record</b>	10.00%	
<b>Percentage of participants that have a discussion about biomarkers/genetic tests</b>	42.00%	
<b>Knowledge of condition and treatments (Partners in Health)</b>	<b>Mean</b>	<b>Median</b>
<b>Knowledge</b>	<b>23.32</b>	<b>24.00</b>
Coping	13.40*	13.00
<b>Recognition and management of symptoms</b>	<b>18.76*</b>	<b>19.00</b>
Adherence to treatment	13.18	14.00
<b>Total score</b>	<b>68.66</b>	<b>71.50</b>
<b>Care Coordination and care received</b>	<b>Mean</b>	<b>Median</b>
<b>Communication</b>	<b>33.40*</b>	<b>36.00</b>
Navigation	22.28*	21.50
<b>Total Score</b>	<b>55.68*</b>	<b>57.00</b>
Care coordination global measure	4.76	5.00
<b>Quality of care global measure</b>	<b>5.52</b>	<b>6.00</b>
<b>Fear of progression</b>	<b>Mean</b>	<b>Median</b>
<b>Total Score</b>	<b>34.10*</b>	<b>34.00</b>

\*Normal distribution, use mean as measure of central tendency