

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:

SUPPORT: As this was a cohort that felt it was important for treatment to be able to control memory loss and cognitive function, fatigue, and pain additional long-term, holistic support would be beneficial. This should include physical, emotional, mental, and medical support particularly for those on long term treatments to support adherence.

COSTS: Transparent information about the costs of treatment is important to this patient population. Cost includes knowing the trajectory of the condition so that they can plan their life and work accordingly and know what costs to expect, especially with private health insurance. This transparent information may help improve quality of life as it was noted that this is a patient population that experienced a negative impact on quality of life largely due to emotional and mental strain on their partners, children, and themselves.

INFORMATION: This is a study cohort that found information about what to expect from the disease, side effects and treatments as being most helpful. They also wished they had known what to expect from their condition especially the disease trajectory and disease biology. To this end, more detailed information about treatment side effects that describes the types of side effects, the impact on day-to-day life, the severity, and how to manage them would benefit this patient population.

2021 PEEK study in Hormone receptor-positive breast cancer

Data collected in this PEEK study also provides a basis on which future interventions and public health initiatives can be based. Some of the 2021 metrics that the sector can work together to improve upon are provided in Table 12.1

Table 12.1 Hormone receptor-positive breast cancer 2021 Metrics

Measure	Detail	Mean	Median
Baseline health (SF36)	Physical functioning	76.83	75.00
	Role functioning/physical	48.56	50.00
	Role functioning/emotional	67.31	83.33
	Energy/fatigue	43.56*	45.00
	Emotional well-being	70.15	72.00
	Social functioning	67.55	75.00
	Pain	60.10	57.50
	General health	60.48*	60.00
Knowledge of condition and treatments (Partners in Health)	Health change	46.63	50.00
	Knowledge	28.00	29.00
	Coping	17.22	18.00
	Recognition and management of symptoms	20.71	21.00
	Adherence to treatment	14.94	15.00
	Total score	80.86*	82.00
Care coordination scale	Communication	45.75*	46.00
	Navigation	26.86*	27.00
	Total score	72.61*	75.00
	Care coordination global measure	8.12	9.00
	Quality of care global measure	8.80	9.00
Fear of progression	Total Score	33.86*	34.00
		Percent	
Accessed My Health Record	-	23.53	-
Participants that had discussions about biomarkers/genetic tests	-	69.23	-